DISTAL SUPPORT IN INDIVIDUALS DIAGNOSED WITH SCHIZOPHRENIA

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Community integration for individuals diagnosed with schizophrenia is essential to successful community tenure. Most of the research and clinical emphasis on the process of integration has been focused on the successes in normative goals (e.g. employment, support networks). Little research has focused on how individuals diagnosed with schizophrenia integrate in the realm of public life involving the casual routine interactions with other community members, termed distal support in this study. This was a cross-sectional study specifically designed to develop a measure of distal support and to identify clinical and sociodemographic factors associated with fostering distal supports.

Findings suggest that personality factors, particularly extraversion and openness, play a role in the process of fostering community distal supports while a higher functional status and lower symptom severity were found to have moderate associations. It was also found that a greater number of distal supports were associated with higher quality of life satisfaction ratings and sense of belonging scores. Contrary to the stated hypothesis, a greater number of distal supports were associated with a higher number of mental health contacts. This may be due, in part, to the confounding effects of the personality factors of extraversion and openness; both associated with a higher number of distal supports and with a greater willingness to seek support and to accept treatment during times of need. A greater understanding of what factors lead to

successful community integration in this population has significant public health implications; both in terms of improved quality of life and treatment interventions.

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I. INTRODUCTION

Schizophrenia is a complex disorder known to have both genetic and environmental causes and is characterized by positive symptoms of psychosis (i.e. hallucinations and delusions), negative symptoms (e.g. social withdrawal, anhedonia), and cognitive impairments (e.g. impaired information processing). A generally accepted etiological model of schizophrenia is the combination of multiple genes and environment factors. With heritability estimates between .80-.84, approximately 20% of the risk is due to the environment (Merikangas, 2003). Although extensive gains have been made in understanding the genetic and neuroenvironmental causes; it nonetheless continues to be an unpreventable disease.

Environmental factors postulated to be of importance to the etiology of schizophrenia include prenatal and perinatal risk factors (early birth, obstetric complications, and prenatal infections) (Cannon, et al. 2003), as well as psychosocial factors (SES, place of birth – urban vs. rural, traditional vs. industrialized society, social supports) (Van Os, et al. 1998).

Global studies of the incidence and prevalence of schizophrenia have confirmed that this disorder occurs across the globe with relative consistency. Prevalence estimates range from 1.4 and 4.6 per 1,000 population at risk (ages 15 to 54) and incidence rates in the range of 0.16-0.42 per 1,000 population at risk per year (Sartorius, 1996, Jablensky, 2000).

Gender differences in course and outcome of schizophrenia have been well documented. It is generally accepted that the age of onset averages 3 - 5 years earlier for males than for

females across cultures. After the age of thirty, the female prevalence rates reach male prevalence rates, resulting in an equal lifetime rate between the sexes (Leung & Chue, 2000). Symptom profiles differ between the sexes with males experiencing more negative symptoms and females experiencing more affective symptoms (Leung & Chue, 2000).

Treatment options include atypical antipsychotics which provide better symptom relief and fewer side effects than the typical antipsychotics, but they are never a sufficient treatment. Social exchange, social roles, and support are central to a healthy and meaningful existence contributing to a sense of belonging and purpose. Yet, the nature of the illness, schizophrenia interferes with the acquisition and maintenance of social resources. Psychotherapeutic interventions have been proven to be effective in reducing relapse rates and hospitalizations, as well as improving quality of life and social adjustment. Cognitive-Behavioral therapy uses both cognitive and behavioral techniques to target attention, memory and executive functions to improve social functioning. Vocational rehabilitation strategies include Sheltered Workshops and Individual Placement and Support models. Nonetheless, there remains more to be learned about the unique social needs of this population outside of the realm of treatment environments.

A review of the literature demonstrates that community integration of individuals returned to the community after long term institutional care has been a focus of research and it is now understood that a degree of community integration is essential to successful community tenure (i.e. living independently in the community) (Carling, 1995). Further, it has become clear that physical integration (i.e. residing in the community versus asylum) does not equate with community integration (i.e. engaging in community life), and that severely and persistently mentally ill individuals need more than what community-based psychiatry can provide to remain

in the community. Most of the research and clinical emphasis on the process of integration has been focused on the successes of rehabilitative strategies that teach the individual to achieve normative goals, as measured by employment rates, network size, and reduced relapse rates. Little research has focused on how the mentally ill integrate outside the domain of the mental health system and in the realm of public life (Beal, 1996).

Studies based on explorations of the 'lived' experience from the perspective of individuals diagnosed with schizophrenia have demonstrated that there is a reluctance to get emotionally involved with others, yet a desire for emotional attachment is present (Sass, 1994). Two recent qualitative studies that examined community integration from the perspective of participants diagnosed with schizophrenia confirmed this phenomenon (Corin & Lauzon, 1992; Beal, 1999). Participants reported enjoying time alone, withdrawn from the demands of every day life, while attaching significance to the daily social interactions provided by frequenting local establishments (restaurants, local stores, libraries) on a routine basis. These social interactions, termed "distal support" in this study, helped the individuals to develop a sense of community and connection.

While qualitative studies have examined the phenomenon of distal supports, this is the first quantitative study designed to investigate the existence of this type of social support and its association with personal characteristics, treatment participation, life satisfaction, sense of belonging, and other factors (e.g. residential status, gender, race, marital status).

II. LITERATURE REVIEW

A. EPIDEMIOLOGY OF SCHIZOPHRENIA

1. Clinical Profile

Beyond the fact that schizophrenia and schizoaffective disorder are relatively rare diseases and thus costly to research, the study of these and other diseases of the brain have inherent difficulties because, unlike diseases involving other organ systems (e.g.heart, kidney disease), there are no physical identifiers or laboratory tests to make a definitive diagnosis. Therefore, the diagnosis of brain disorders is based on the diagnostician's interpretation of each patient's subjective self-report (Jones, 1996), and patient examination, as well as collateral information from individuals involved in the patient's life.

Until a more standardized criteria was published in the Diagnostic and Statistical Manual (DSM) in the United States and the International Classification of Diseases (ICD), the widely divergent diagnostic criteria worldwide resulted in serious methodological limitations in research. The DSM III and subsequent editions contains criteria-based definitions of psychiatric disorders, which were the result of consensus building from a large number of psychiatrists of many different perspectives and belief systems from all over the world. Definitions are regularly being revised as research and other information becomes available. The DSM IV-R is the latest edition. The ICD was designed for the classification of morbidity and mortality information for statistical purposes, and published by the World Health Organization (WHO). The WHO revises

the codes approximately every 10 years, with annual updates published by the Centers for Medicare and Medicaid Services (formerly known as the Health Care Financing Administration (HCFA)), the most recent edition is the ICD-10. The DSM and ICD publications became the guideline for making the diagnosis of schizophrenia thereby assuring greater uniformity (Jones, 1996).

Schizophrenia is characterized by profound disruptions in cognition and emotion. It influences the most fundamental human attributes of language, thought, perception, affect, and sense of self. The range of symptoms frequently include psychotic expressions of auditory, visual and, less commonly, olfactory, gustatory, and tactile hallucinations, as well as delusions in which fixed false beliefs are held or special significance or meaning is given to normal events. No single symptom is definitive for diagnosis, and is evaluated by both the symptom presentation, mental state examination, and impaired occupational or social functioning. Course and recovery, as with other mental disorders, is determined by a combination of biological, psychological, and sociocultural factors (Pull, 1999).

Symptoms are typically divided between positive and negative, each affecting course and outcome differently. Positive symptoms reflect a distortion of normal functioning while negative symptoms are those that reflect a decrease or loss of normal functioning, often persisting during periods when positive symptoms are reduced or absent. Negative symptoms are more difficult to discriminate because they are not as obviously abnormal as positive symptoms and may be caused by a variety of other factors such as an adaptation to a persecutory delusion or reaction to medications (Pull, 1999).

Generalized cognitive deficits are also present in schizophrenia. Neuropsychological deficits are prominent on tests of complex conceptual reasoning, psychomotor speed, new learning and incidental memory, and both motor and sensory perceptual abilities. Attentional dysfunctions are found in immediate attention span, sustained attention, visual search and tracking, selective attention, and executive control of attention. Impairment in problem solving when novel solutions are required or when solutions are not readily apparent is common (Pull, 1999).

Subtypes of schizophrenia have been identified to account for the widely varied symptom expressions of this disorder and include paranoid, catatonic, and undifferentiated. To confirm a diagnosis of schizophrenia, regardless of subtype, two or more of the following symptoms must be present for a significant portion of a one-month period: delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behavior, and negative symptoms (flat affect, avolition, or alogia). The inclusion of a minimum duration of symptoms (one month) has been added to allow sufficient time for symptoms to appear and remit before a diagnosis of schizophrenia is made to differentiate from the diagnosis of brief psychotic disorder (Jones, 1996).

The diagnosis of schizoaffective disorder is made when a patient has features of both schizophrenia (hallucinations, delusions, distorted thinking) and a mood disorder (depression or mania). Two subtypes have been identified: bipolar and depressive**.** The DSM-IV specifies that the diagnosis of schizoaffective disorder can be made when symptom criteria for schizophrenia are met and there is a major depressive, manic, or mixed episode during the same continuous period. In addition, a 2-week period during which the individual experiences positive symptoms must be present when there are no mood symptoms (American Psychiatric Association, 1994).

Schizoaffective disorder is more common in women than in men and usually begins in late adolescence or early adulthood. There have been no racial differences found in the incidence or prevalence of this disorder (Brannon, 2003). Schizoaffective disorder is speculated to be a form of schizophrenia (Evans, et al, 1999) or "a genetically heterogeneous condition primarily composed of schizophrenia, unipolar and bipolar disorders and perhaps a residual currently undifferentiated condition"…"Growing evidence suggests that symptoms of psychosis may be a common end-state in a variety of disorders, including schizophrenia, rather than a reflection of the specific etiology of schizophrenia (Tsuang, et al., 1974).

2. Incidence and Prevalence

Incidence estimates of schizophrenia are challenging for the reasons outlined above, as well as the difficulty in identifying the actual onset of the disease from a biochemical or cerebral dysfunction standpoint. Therefore, clinical manifestations leading to psychiatric care are the most commonly used measure of time of onset. Often, however, there is a delay between clinical manifestations of the illness and the time of first contact with health services. The date of first contact with a provider is found to be more accurate than the date of first hospitalization due to present-day changes in diagnostic trends (e.g. one month duration of illness before diagnosis is made) and a greater preference to treat patients in the community versus acute inpatient care (Jablensky, 2000). The standardization of criteria has allowed for improved estimations of the prevalence of schizophrenia. The majority of studies have produced lifetime prevalence rates of 5.5 per 1,000 and 11. 1 per 100,000 1-year incidence rates estimates (Goldner et.al., 2002), with some variance among certain population groups with unusually high prevalence rates (isolate populations in Sweden, several areas of Finland and an area in Croatia) and low prevalence rates

(the Hutterites in South Dakota). The degree of the variations in prevalence, however, is small compared to other multifactorial diseases such as ischemic heart disease, diabetes, and multiple sclerosis (Jablensky, 2000). Global studies of the incidence and prevalence of schizophrenia has confirmed that this disorder does occur across the globe with relative consistency. The World Health Organization (WHO) conducted the largest and only comparable incidence data for different populations. From this study, prevalence estimates were found to range between 1.4 and 4.6 per 1,000 population at risk (ages 15 to 54) and incidence rates in the range of 0.16-0.42 per 1,000 population at risk (Jablensky, 2000). In the United States the lifetime prevalence of schizoaffective disorder is estimated to be less than 1% (Evans, 1999).

Several studies have reported a decline in the incidence rate of schizophrenia in the developed countries of Scotland, England, Wales, New Zealand, Finland, and Denmark over the last four decades (Suvisaari, et.al, 1999; Eagles, et.al, 1988; 1993; Munk-Jorgensen, 1995; Bresnahan, et al., 2003), as well as Canada (Woogh, 2002). The decline in incidence suggests a cohort or period effect with an important role played by the social environment. A comparison study of two first-episode cohorts (1978-80 and 1992-94) in England found a small but statistically significant decline in the incidence of narrowly defined schizophrenia, but an increase in acute and drug-related psychoses in the second cohort. Overall, the rate of broadly defined schizophrenia increased slightly (from 2.49 to 2.87 per 10,000) and the rate of narrowly defined schizophrenia decreased significantly (1.41 to 0.86 per 10,000). The presentation of symptoms showed a greater diversity in the second cohort (Brewin et al., 1997).

Although it is unclear what specific effects are at play, a reasonable explanation is that overall improvements in health practices and services (e.g. prenatal nutrition, maternal

immunization and infection control) resulting from the improved socioeconomic conditions in these countries (Bresnahan et al, 2003). Possible confounding explanations for the finding of a decreased incident include the more restrictive criteria for the diagnosis of schizophrenia, the emphasis placed on community versus in-patient care (when hospital admission rates are the source of data), the clinical decision to wait to make the diagnosis of schizophrenia after the individual has been more extensively followed, and overlooked changes in population age, sex, and ethnic structures (Jablensky, 2000).

While lower incidence rates are found in the developed countries discussed above, higher rates have been found among African-Caribbean minority immigrants to London compared to both the population of origin and the British population (Boydell, et.al, 2003; Takei, et.al, 1998) and to Sweden (Zolkowska, et.al, 2001; Mortenson, et.al., 1997), suggesting environmental factors. One explanation postulated is that African-Caribbean immigrants suffer from a "type of psychosis" distinct from schizophrenia, although this has not been substantiated. Environmental explanations include body weight of the infant, viral exposure**,** sociocultural factors of single-parent families, poor school achievement, high unemployment, and less social support, and lack of community integration. Questions of why the same environmental factors are more likely to result in neurotic disorders in the indigenous white population and why other immigrant groups (e.g. Asians) are not also found to be at increased risk of schizophrenia remain unanswered. A closer examination of this finding led to doubts as to whether there actually is a higher prevalence of schizophrenia in the African-Caribbean population, but instead a lower threshold for making the diagnosis of schizophrenia due to the factors of a greater affective component, a higher number of relapses with a remitting course, and fewer negative symptoms resulting in more social disruptions than the indigenous English population. These questions underscore the

need to more extensively study these findings before conclusions can be made (Sharpley et.al, 2001).

3. Patient Characteristic

a. Gender Differences

Gender differences in course and outcome of schizophrenia have been well documented. It is generally accepted that the age of onset averages 3 - 5 years earlier for males than for females across cultures (Leung, 2000). Help-seeking behavioral differences between the sexes, definition of time of onset, diagnostic criteria (ICD vs. DSM) and population age differences did not account for the younger age of onset in males when statistically controlled. The age of onset differences disappear only in familial schizophrenia (Leung, 2000). A higher risk of developing schizophrenia at an earlier age in females, however, was found in a study conducted in India (Murthy, 1998).

The incidence curves of schizophrenia differ between the sexes; males have a single distinct peak of onset between the ages of 15-25 followed by a steady decline. Females have a broader peak age of onset between the ages of 15 and 30, followed by a second smaller peak between the ages of 45 and 49, and a third peak over the age of 65. After the age of thirty, the female prevalence rates reach male prevalence rates, resulting in an equal lifetime rate between the sexes. The overall incidence rate is found to be lower in females only when diagnostic criteria involves an age limit and is narrowed in terms of severity and duration of symptoms. Women have a relative risk of late onset schizophrenia (age > 40) of 2-3 times higher than men (Leung, 2000). No explanation for this difference has been confirmed, but a protective effect of

the female sex hormones estrogen is one proposed explanation (Jones, 1996). The role of decreased levels of estrogen during menopause suggests that estrogen may act as an endogenous antipsychotic, postponing symptoms of schizophrenia in women who are at genetic risk (Palmer, et.al, 2001).

Controlling for the confounding variables of marital status and premorbid personality has eliminated the age difference in some studies, though the findings are not consistent across studies. A longitudinal cross cultural study that controlled for marital status found that marriage had a protective effect in delaying age of onset (Jablensky & Cole, 1997), another study found marital status to be protective primarily in males in delaying the age of onset (Haffner, et.al., 1989). The Epidemiological Catchment Area study found that people with an unmarried status were at a 14 fold increased likelihood of developing schizophrenia in women and 50 fold in men over married individuals (Tien et.al, 1992). Another study also using case register data, however, had findings consistent with an earlier age of onset in males even after controlling for marital status and premorbid functioning (Castle, et.al, 1992). These studies did not discuss the confounding effect of premorbid functioning and type of onset (acute vs. insidious) that may account for differences in marital status.

Symptom profiles differ between the sexes; generally, most evidence suggests that men experience more negative symptoms and women experience more affective symptoms. Differences in positive symptoms (hallucinations, delusions) are not pronounced between men and women, but women experience more auditory hallucinations and persecutory delusions. Diagnostic concordance rates are lower in women than in men due to the more pronounced affective and cyclical symptomatology in women (Leung & Chue, 2000). A review of North

American long-term follow-up studies found that female gender is predictive of a better course and outcome in areas of symptomatology, substance use, and global functioning (McGlashan, 1998).

b. Developmental abnormalities

Developmental abnormalities beginning in the neonatal period have been demonstrated in several longitudinal and high-risk studies. High rates of these abnormalities in subjects who later developed schizophrenia were found in all stages of early life; during the neonatal period hypoactivity, erratic alertness, hypotonia, and poor cuddling were common; early childhood was often characterized by poor motor coordination, gross motor skill deficits and solitary activity; later childhood was characterized by informational and attentional deficits, lower education test scores, speech problems, poor peer engagement and social unpopularity (Jones, 1997; Hans, 1999; Erlenmeyer-Kimling et.al., 1987; Fish, 1977; Davidson, et.al., 1999; Beardon, 2000; Russo, 2000).

4. Risk Factors

a. Neurodevelopmental factors

Early brain development deviance with full adverse effects undetected until adolescence or early adulthood is central to the neurodevelopmental hypothesis of schizophrenia that postulates that early brain development abnormalities increase the likelihood of schizophrenia in adult life. This theory was generated after observations revealed a pattern of abnormalities in neurological and behavioral characteristics during childhood, pathological examination of

developmental abnormalities in the hippocampus, and neuroimaging findings of cerebral ventricular enlargement (Weinberger, et.al, 2002). It is hypothesized that insults occurring during fetal development, caused by heredity and/or environmental factors, results in a static encephalopathy that is manifested in psychosis after factors in adolescence or young adulthood have allowed its full expression. Environmental insults considered include prenatal exposure to virus', starvation, rhesus and ABO blood-type incompatibility, and obstetric complications (Arnold, 1999).

Early evidence supported this hypothesis with findings of ventricular enlargement that did not appear to progress into adulthood. A review of early MRI studies published between the years 1988-2000 found that lateral ventricular enlargement was found in 80% of the studies, third ventricular enlargement was found in 73% of the studies, medial temporal lobe volume reductions in 74% of studies, including amygdala, hippocampus, and parahippocampal gyrus, and neocortial superior temporal gyrus volume reductions in 100% of studies (Shenton, et. al, 2001).

In another longitudinal study (Lawrie, et.al, 2002) of at risk family members and controls, abnormalities were found in the temporal lobe structures in the at-risk individuals, with no changes over time. In individuals who developed psychotic symptoms, changes in these structures did occur, suggesting that changes occur only in individuals who proceed to psychosis. Historically the neurodegenerative and neurodevelopmental hypothesis were viewed as mutually exclusive, but this recent evidence is suggestive of a disease characterized by both processes (Niznikiewicz, et.al, 2003). These findings require more definitive evidence and further studies are needed (Weinberger, et.al, 2002).

Researchers have examined developmental deficits in the early years of life. High-risk studies have identified childhood manifestations of neurobehavioral memory, attentional, and gross motor skills deficits. The New York high risk study followed offspring of schizophrenic parents longitudinally and found developmental abnormalities during the neonatal period, infancy, early childhood and late childhood in 25-56 % of high risk children based on test results in verbal memory (83%), attention (58%), and gross motor skills (75%) (Erlenmeyer-Kimling et.al., 1987). During the neonatal period, hypoactivity, erratic alertness, hypotonia and poor physical coddling were apparent. During early childhood poor motor coordination was noted. In later childhood information processing and attentional deficits were found (Jones, 1997). Fish (1977) coined the term 'pandymaturation' to describe the disordered pattern of acquisition of developmental milestones. Overall 50% of the offspring of schizophrenic parents who developed schizophrenia-related psychosis had deficits in the three childhood measures of verbal memory, gross motor skills, and attention. 10% of the offspring of schizophrenic parents who did not later develop schizophrenia-related disorders also had deficits in these measures. This may indicate that these individuals are carriers of at least some of the schizophrenia-susceptibility genes and may be useful to future gene finding studies (Erlenmeyer-Kimling, 2001). The Jerusalem Infant Development Study, also a prospective examination of offspring of schizophrenic parents, found disproportionately poor neurobehavioral functioning in 42% of the offspring of these parents (Hans, et.al., 1999) and found social deficits characterized by poor peer engagement and social unpopularity. These deficits were not attributed to early onset of mental disorders (Hans, et.al., 2000).

Larger population-based studies have replicated these findings, most notably the National Survey of Health and Development study (Jones, et.al., 1994). These researchers found that 30

of the 5,326 individuals from this birth cohort who later developed psychotic disorders experienced a greater delay in reaching motor development milestones, more speech problems, lower educational test scores, and more solitary activity. A case registry study linked draft board test results from the Israeli Draftees to the National Psychiatric Hospitalization Case Registry and found significantly lower test scores on all measures among individuals who later were treated for schizophrenia compared to matched non-patients. The strongest predictors were deficits in social functioning, organizational ability, and intellectual functioning (Davidson, et.al., 1999). The National Collaborative Perinatal Project, a prospective cohort study, examined IQ scores at ages 4, 7, and 23 and found that greater than expected IQ declines during childhood were a predictor of developing psychotic symptoms (Kremen, et.al., 1998). Other studies, examining schizophrenic patients and their unaffected siblings, reported pathological processes of social maladjustment, focal deviant behaviors (e.g. echolalia, meaningless laughter), unintelligible speech and poor expressive language ability (Bearden, 2000), and neuromotor dysfunction deviations were found by age 7 (Rosso, 2000). These were found to be significant predictors of schizophrenia. Both deviant motor coordination and poor expressive language ability were also evident in unaffected siblings, suggesting a familial factor, possibly genetic (Bearden, 2000, Russo, 2000).

It is now decisively understood that there are neurodevelopmental deficits prior to the expression of schizophrenia. These symptoms could be unrelated to the full-blown disorder of schizophrenia and it is not understood whether they represent a vulnerability to the disorder of schizophrenia, are a separate disorder, or whether they are early manifestations of schizophrenia (Jones, 1997).

b. Genetic factors

It is undisputed that genetic vulnerability plays an important role in the etiology of schizophrenia. Twin concordance rate is close to 50% for monozygotic twins and 10-15% for dizygotic twins, the same risk for full siblings. First-degree relatives have approximately a 10% risk of developing schizophrenia, offspring of two schizophrenic parents have a 50% risk, of one schizophrenic parent a 13% risk, first cousins a 2% risk and the general population has risk of ~ 1% (Jablensky, 2000). Heritability estimates for schizophrenia have been consistently found to be between .80-.84 (Merikangas, 2003). Heritability estimates define the proportion of phenotypic variance attributable to genetic variance and the extent to which genetic individual differences contribute to individual differences in phenotypes. Heritability estimates range from 0.0 (no genetic contribution) to 1.0 (genes are the only cause of the individual differences). According to the above heritability estimate of schizophrenia, .16 to .20 of the variance in schizophrenia is due to environmental factors.

Family studies involving multiply affected members have been conducted in an effort to identify the specific putative genes have been a successful approach with common disorders such as breast cancer and insulin-dependent diabetes mellitus, yet have not met with the same success in the study of schizophrenia. Systematic genomic searches have made clear that schizophrenia is not a single-gene disorder. Linkage studies (successful in mapping the genes for Huntington's disease) and allelic-association studies (successful in the study of Alzheimer's disease) have only modest initial findings in providing evidence of several chromosomal regions in the disorders of

both bipolar and schizophrenia. Candidate genes are particularly hard to find for schizophrenia due to the fact that its pathophysiology is little understood. The success of genetic studies depends on the validity of phenotypes under study. To date, identifying genetically distinct subtypes within the major diagnostic categories has not been possible. The clinical variation found in schizophrenia is thought to be reflective of a combination of quantitative variation in genetic risk and the effect of modifying genes that influence the expression of the illness rather than the risk alone (Owen, 2004).

Genetic factors, however, are not sufficient to cause schizophrenia, as evidenced by discordant rates in monozygotic twins. Environmental influences have been examined extensively with some success.

c. Environmental factors

Prenatal risk factors include season (winter and spring) and place of birth (urban-rural); prenatal influenza as well as other bacterial and viral exposures; prenatal famine; rhesus incompatibility; and prenatal stress, as well as perinatal risk factors including obstetric complications such as premature rupture of membranes, gestational age less than 37 weeks, hypoxia-related complications, and pre-eclampsia. The risk factors most consistently found are prenatal exposures to influenza and other infections during the second trimester including prenatal rubella (the greater frequency of births in this population during the winter and spring months are thought to place the fetus at higher risk of infection during gestation), hypoxia-related obstetric complications (OCs), and low birth weight (Cannon, et al. 2003). Studies demonstrate increasing evidence of the risks of OCs as a cause of deficits in brain development

that eventually lead to the later onset of schizophrenia. Many studies have concluded that OCs produce an effect only thorough interaction with an existing genetic risk (Shepherd et al, 1989). A 28-year follow-up study of a Finnish birth cohort has shown that children with perinatal brain damage (i.e. defined as neonatal convulsion, low Apgar scores, asphyxia, intraventricular hemorrhage, or abnormal neurological findings) are 7 times more likely to develop schizophrenia in adulthood than others in the cohort (Jones et.al, 1998). The Copenhagen high-risk study demonstrated that among the offspring of schizophrenic mothers, a larger percentage of individuals who later developed schizophrenia had a history of birth complications than did those in the low-risk group. This suggests a dose-response risk for the disease (Cannon, et.al, 1993).

d. Gene-Environment Interaction

Increasing evidence is mounting to support the gene-environment theory as relevant to the disease of schizophrenia. It is known that schizophrenia does not follow a Mendelian mode of transmission and it is likely that multiple genes are involved, each with a relatively small effect on the liability to schizophrenia. A twin study in Finland found that 83% of the variance in liability to schizophrenia is caused by additive genetic factors, and the remaining 17% are caused by environmental factors (Tiernari, 1991). Other studies give a lower overall heritability estimate at 68% (Jablensky, 1995).

One generally accepted etiological model for schizophrenia is a combination of multiple genes and environmental factors. The stress-diathesis model proposes that an environmental factor must be present to realize the genotypic susceptibility to schizophrenia. The effect sizes for prenatal, perinatal, and genetic risk factors are relatively small, but taken together suggest

that schizophrenia involves the interactive effects of early environment and genetics (Cannon, et al, 2003). Predisposing genes may remain unexpressed in the absence of environmental exposures that promote susceptibility during the gestational and birth processes, leading to neurodevelopmental aspects of schizophrenia.

e. Social factors

Socioeconomic status (SES) and high levels of urbanicity have been postulated as risk factors to schizophrenia. Socioeconomic status as a causal explanation of differences in health status among hierarchical classes has been well accepted and numerous studies have demonstrated an inverse relationship between SES and health (Adler et al, 1999; Baum et.al, 1999; Roberts, 1998; Marmot, 1998). The social class indicators of income, occupation and education have been recognized to be factors in determining the public's mental health. Persons of lower socioeconomic status do not have the benefits of material well being, predictability and control over one's life that are afforded to persons in the higher SES brackets (Muntaner et al., 1998). Few studies have examined SES in relation to risk for schizophrenia. In one, in a study examining social deprivation and the incidence of psychosis and rates of psychiatric hospital admission, higher than expected rates were found among the general population residing in an area of high social deprivation (Croudace et.al, 2000). Marmot (1998) made a distinction between relative and absolute deprivation, pointing out that deprivation in industrial societies most often doesn't mean the lack of adequate nutrition, housing and other necessities of life, but instead is defined relative to what others have. Material deprivation in a modern perspective may mean the inability to participate fully in society and to control one's life. Generally, most studies have examined the influence of SES on disease susceptibility, but SES may also be of

importance to the course and outcome of disease (Adler et.al, 1999). Despite the extensive research, the reasons for poorer health status are not well understood. Conventional explanations, such as poor sanitation, poor diet, negative health habits, and low physical activity levels do not explain the full extent of disease susceptibility.

Psychosocial aspects of SES differences contribute significantly to health status. In a study that measured cultural dimensions of social support, the researchers discovered that those individual's with a lower SES who aspired to a higher status lifestyle experienced higher blood pressure, greater perceived stress, and more symptoms of depression (Dressler, 1998). An examination of these influences has implications for the study of schizophrenia. In keeping with this finding, Corin and Lauzon (1992) found that study participants who did not aspire to normative roles had a greater stability in the community with fewer hospitalizations.

Urban living has long been examined as a risk factor to schizophrenia. The earlier hypothesis that social drift accounted for the different rates has been disputed by recent research that took into account where individuals were born and reared, demonstrating that inner-city factors earlier in development create a higher risk for schizophrenia and that environmental and social factors are likely to have a role (Buszewicz, 1994). A study that examined urbanicity at the time of illness onset demonstrated that the influence of urbanization posed the greatest risk early in the lifespan and before the onset of illness (Marcelis, et al, 1999). Variations in the prevalence of mental disorders between different urban neighborhoods have also been found, yet there has been no agreement about the interpretation of these findings. A recent study found a dose-response relationship between urbanicity and risk of schizophrenia. Individuals who were currently living in a higher level of urbanization than 5 years earlier were at a 1.4 fold increased

risk of schizophrenia, while those who were living in a lower level of urbanization than 5 years earlier were at a 0.82-fold decreased risk of developing schizophrenia. Risk for schizophrenia was greater among those with the most time living in an urban area and with degree of urbanization. Those who were reared in the highest category of urbanization during their first 15 years of life were at a 2.75-fold increased risk of schizophrenia (Pedersen, et.al., 2001).

5. Treatment

The biopsychosocial approach to treatment recognizes the interactions of the biological, psychological and sociological factors affecting the individual. Treatment based on this model provides interventions with a focus on improving behavior, cognition, and social skills, as well as the reduction in symptoms (Bachrach, 2000).

Antipsychotic medications have been shown to be effective in alleviating psychotic symptoms and preventing relapse. Antipyschotics are classified as typical or first generation if the risk of extrapyramidal symptoms is elevated (tardive dyskinesia, parkinsonian symptoms of stiffness, rigidity and tremors (Bustillo et al, 2001). The "second generation" antipsychotic medications were approved in the 1990s and pose a reduced risk of extrapyramidal symptoms. In clinical trials Clozopine was found to be more effective than the first generation antipsychotics in individuals with treatment resistant schizophrenia (schizophrenia that has not responded to other drugs), and the risk of tardive dyskinesia (a movement disorder) was considerably lower, but the risk for agranulocytosis, an often fatal condition, makes this a less likely first line of treatment. Initially, the second generation medications were prescribed only for treatment resistant patients due to the higher costs of these drugs, but as studies emerged

demonstrating fewer side effects and improved adherence to treatment recommendations, they are now more widely accepted as a first-line treatment (Bustillo et al, 2001).

The more recently introduced antipsychotic medications show the greatest promise for improving cognition, possibly due to lower extrapyramidal side effects, as an effective agent in controlling glutamime levels that cause an increase in acetylcholine levels and are more effective in reducing depressive symptoms. A negative effect of some of the atypical antipsychotics, however, is an appetite inducing effect and consequent weight gain (Maguire, 2002).

Despite the gains made with the newer medications, the majority of patients, even those who have a good response to medication, continue to have disabling residual symptoms, impaired functioning, and risk of relapse. Evidence has demonstrated that psychosocial interventions in schizophrenia are effective in reducing relapse rates and hospitalizations, improving quality of life and social adjustment, as well as enhanced vocational success (Bachrach, 2000). The most fundamental definition of psychosocial rehabilitation is that it is a therapeutic approach designed to help individuals with mental illnesses to develop to their highest potential in an educational and supportive environment. Social skills therapy offers training in specific skills (e.g. stress management, assertiveness, communication, problem solving) to increase the individual's ability to function. Cognitive therapy helps the individual to use information from the world (e.g. interactions with other people, perceptions of events) to make adaptive decisions to improve the management of life problems, function independently, and to reduce distress caused by the symptoms of the illness.

Randomized controlled trials have provided impressive evidence of the effectiveness of cognitive-behavioral therapy in treating psychotic symptoms (Drury, et al, 1996, Tarrier et al

1993, Garety et al. 1997, Kuipers et al, 1997, 1998, Sensky, et al, 2000, Rector, et al, 2003). A randomized trial of Integrated Psychological Therapy (IPT), a -therapeutic approach targeting neurocognitive functions to improve social skills and interpersonal problem solving also demonstrated positive effects (Spaulding, 1999). Personal therapy (PT) has been demonstrated to produce the significant and enduring effects of improved social adjustment, reduced relapse rates, and progressive improvement in psychosocial adjustment (Hogarty, et.al, 1997). Cognitive Enhancement Therapy (CET) offers great promise for lasting and broad improvements in cognitive functioning for patient diagnosed with schizophrenia. It is a newer therapy that is distinguished from behavioral skills training programs in that it involves a more developmental than behavioral process. CET focuses on functional cognitive disabilities and social handicaps using a developmental versus a behavioral process. Its goals are to promote social developmental milestones with "gistful", rather than verbatim, responses in social situations; socialization competencies in an unrehearsed social context; education and understanding of each patient's social and non-social cognitive deficits; and the use of an experiential interactive process to address cognitive deficits on behavior. This is achieved by providing personally meaningful and self-directed experiences rather than practiced instruction and role-playing as found in traditional cognitive therapy (Hogarty & Flesher, 1999). Results of a 2-year randomized trial of CET involving neuropsychological and behavioral assessments at baseline and at 12 and 24 months demonstrated significant effects on all measured domains of behavior and cognition (i.e. processing speed, neurocognition, cognitive style, social cognition, and social adjustment) (Hogarty, et.al., 2004)

There are multiple benefits from employment for patients with schizophrenia including increased income, structured days, increased socialization, the development and use of skills,

social responsibility, and improved self-esteem (Twamley et al, 2003). Types of work rehabilitation programs include sheltered workshops, most often involving assembly or packing functions in a segregated sheltered setting; psychosocial rehabilitation programs involving prevocational training classes, transitional employment or volunteer placement; supported employment in which patients are trained on the job in integrated work settings and earn a competitive wage (Twamley et al, 2003).

Patients diagnosed with schizophrenia residing in the community receive treatment from a fragmented system of various provider services and often have difficulty identifying, securing, and negotiating these services. Case management programs were funded in an effort to provide *'in vivo'* individualized support from a case manager with whom the patient ideally forms a therapeutic alliance. Resource Coordinators (RC) and Intensive Case Managers (ICM) conduct needs assessments and linkage to needed services. In addition they monitor clinical status and provide supportive counseling. RCs generally work with higher functioning clients and limit most of their activities to needs identification and linkage and have fewer monthly contacts. ICMs provide more intensive services to generally lower functioning patients and have more frequent monthly contact based upon need. The Continuous Treatment Team (CTT) is a multidisciplinary approach involving nurses, psychiatrists, and case managers working with the client in the community as a team. This service is generally provided to clients who have difficulty with traditional treatment provision and contact is often made daily.

Even with the substantial evidence that the best possible interventions for recovery in schizophrenia requires the integration of medication and psychosocial treatment, insufficient resources are given to psychotherapeutic interventions. Schizophrenia is a disorder that has a

varied presentation and course. Therapeutic interventions need to be tailored to the specific needs of the individual, as offered by PT and CET, to promote lasting recovery. Community support models such as intensive case management and CTT, are also essential to recovery by facilitating stable and secure living situations so that individuals can focus on psychosocial treatments free of the insecurities and discomforts brought on by deprivation and neglect.

6. Morbidity and Mortality

There is considerable evidence behind the description of schizophrenia as a "life-shortening disease" (Allebeck, 1989). Epidemiological studies have consistently found higher rates of early mortality among persons with schizophrenia at a level of more than twice that of the general population (Waddington, 1998).

Suicide is the single largest cause of premature death in this population; 1 in 10 persons diagnosed with schizophrenia will end their own life. The lifetime risk of major depressive disorder in patients with schizophrenia is 60%, an 8-26% increased lifetime risk compared to the general population (Maquire, 2002). The incidence of suicide is highest among patients' diagnosed with paranoid schizophrenia (12% elevated risk of suicide) and lowest among patients with predominantly negative symptoms (1.5%) (Fenton, 1997).

Medical comorbidity in schizophrenia accounts for 60% of the premature deaths not related to suicide in this population. Causes for high morbidity rates include life-style factors (smoking, poor diet, lack of exercise, and alcohol consumption). Common medical conditions found in patients with schizophrenia include diabetes (risks are increased by poor diet and sedentary behavior as well as atypical antipsychotic medications), hyperlipidemia (related to

atypical antipsychotic medications), cardiovascular disease and respiratory disorders (related to antipsychotics, life-style factors), obesity (40-62% of schizophrenic patients are overweight), and cancer (although the likelihood of developing cancer is no higher than the general population, survival rates are reduced by 50%). Increased prevalence of HIV/AIDS, Hepatitis C, Osteoporosis, Hyperprolactemia, Irritable Bowel Syndrome, and Helicobacter pylori infection are also found (Lambert, 2003).

Another reason for the high rates of morbidity in schizophrenia is the barrier to access to health care and consequent inadequate treatment. Patient characteristics that create barriers include the lack of reporting illness and neglecting to seek medical treatment, poor treatment compliance, and unawareness of medical problems due to cognitive deficits or high pain tolerance. Provider barriers include frequent changes in health care staff and the consequent lack of continuity in care, lack of follow-up to identified medical problems, reluctance on the part of psychiatrists to attend to medical illnesses, the regarding of medical complaints as psychosomatic, and the lack of available time and resources in the current health care climate (Lambert, 2003). A lack of adequate care to patients with schizophrenia is due to a poor record of recognizing and treating medical condition in schizophrenic patients on the part of both general practitioners and psychiatrists (Osborn, 2001)

7. Course and Outcome

Outcome in schizophrenia is measured using both clinical and social effects and requires a longitudinal assessment of patients defined at various time points following initial diagnosis (Bresnahan et al, 2003). Course and outcome studies have demonstrated remarkable variability and are particularly difficult to summarize due to varying definitions of outcome and the

measurement methods used (Jones, 1996), in addition to the lack of identifying a cohort in terms of illness duration (Ram et al, 1992). Generally, however, studies have concluded that one-third of patients will fully recover (minimal to no residual symptoms), one-third will have improvement, but not a full recovery, and one- third will remain seriously and persistently ill (Jones, 1996).

The long-term follow-up study of the Washington cohort of the International Pilot Study of Schizophrenia (IPSS) found that symptom severity, duration of hospitalization, and work and social functioning at both the 2 and 5-year follow-up were most predictive of long-term follow-up. Additionally, overall measures of functioning at 11 years did not differ from functioning at 2 and 5-year follow-up, providing evidence that deterioration is not inevitable, but instead that stability in functioning following initial deterioration or even improvement can be expected Sartorius, et.al., 1996). This finding was confirmed in a subsequent study (Davidson & McGlashan, 1997). Below is a review of the findings of longitudinal studies.

McGlashan (1998), in his review of 10 North American long-term follow-up studies, concluded that although schizophrenia is a chronic disease that can be disabling over the course of a lifetime and with outcomes worse than other major mental illnesses (bipolar, major depressive disorder), deterioration levels drop off after the first 5-10 years of onset; patients suffering from schizophrenia are at greater risk of suicide and co-morbid conditions; rehabilitative and supportive environments can be successful at improving outcomes if applied gradually and not too intensively; and that although long-term studies demonstrate a wide variability in outcomes, much of this can be attributed to the sampling method – diagnostic criteria used (broad vs. narrow, subtype of schizophrenia); dimensions of illness (age of onset,

duration of illness), and demographic characteristics identified as predictive of outcome (gender, marital status, SES, premorbid functioning). Furthermore, the diagnostic criteria used can have prognostic implications (e.g. criteria involving duration of psychotic symptoms) (McGlashan, 1998).

A more recent meta-analysis of follow-up studies beginning with 1988 publications of studies conducted in North American and Europe again found wide heterogeneity in outcomes, with good outcomes (i.e. mild impairment to complete recovery) ranging from 21-57%. The conclusions reached by this meta-analysis includes evidence that most deterioration in functioning occurs with the first few years of the onset of illness and is followed by stability or improvement over the later course of the illness; affective symptoms and depression were found to be predictive of a better outcome, indicating that the more narrow the criteria used, the less favorable the outcome; negative symptoms were found to be predictive of a poor outcome, as well as cognitive impairments and reduced functional capacities; assertive rehabilitation efforts do improve outcomes; and later and acute onset as well as a positive response to medications early in the course of the illness is prognostic of a better outcome (Davidson & McGlashan, 1997). Predictor variables of a good prognosis have emerged from the numerous longitudinal studies conducted and include a family environment characterized by low expressed emotion (EE), medication compliance, being married, florid psychotic episode at the time of first admission, and good premorbid functioning (Ram et al, 1992).

One of the shortcomings of the majority of longitudinal outcome studies is that recruitment is based on consecutive admissions and therefore lacked clinical homogeneity in terms of duration of illness. First-episode studies address this limitation by following the patient

beginning at the onset of the illness. Findings from first-episode studies are that relapse rates are about 60% during the subsequent 2-years. Predictor variables of a better outcome included good premorbid social and work functioning, acute onset (vs. insidious), treatment earlier in the course of the illness, and rapid response to medications (Ram et al, 1992).

a. Cultural influences

Cross-cultural differences in outcomes between Western and non-Western societies were noted early on, yet the majority of these earlier studies were cross sectional and conducted prior to the introduction of the uniform DSM and ICD criteria guidelines, thereby leaving significant doubts about the findings of a more benign course in non-Western societies. Later follow-up studies with more sophisticated measurements and the application of research methods used in Western countries helped to further ascertain the finding of better overall outcomes in developing nations, but extreme variability in the findings still did not allow for a conclusion. For instance, of the 30 studies that reported recovery rates, complete recovery in Western studies had ranges from 9-52%, in the non-Western studies the rates ranged from 17-46% (Lin & Kleinman, 1988).

The WHO International Pilot Study of Schizophrenia (IPSS) began in 1967 with the goal of exploring the presence of schizophrenia throughout the world and to investigate the course and outcome in different cultures and confirmed that similar syndromes of schizophrenia occur throughout the world; and that the participants in the three non-Western societies had significantly better outcomes than the patients residing in the Western societies. However, differences in attrition rates across centers and re-diagnosis at follow-up between centers allowed for potential bias, as well as the fact that non-clinical factors, such as premorbid personality,

social and occupational functioning (variables know to effect prognosis) were not taken into consideration (Lin & Kleinman, 1988).

This study was followed up by the Determinants of Outcome of Serious Mental Disorders (DOSMD) (Jablensky, 1992) study with a greater focus on the frequency and natural history of schizophrenia as well as the psychosocial influences on course and outcome and involved 10 countries. This was an incidence-based (measured as the annual rate of first-in-lifetime contact with any type of service or helping agency, including traditional healers) sample therefore each participant was followed from the time of onset. The DOSMD replicated the findings of the IPSS study of the occurrence of similar syndromes of schizophrenia throughout the world and better outcomes in developing countries – the proportion of individuals with a remitting course (with symptom free intervals) was observed in 62.7% of patients in the developing countries as compared to 36.8% in the developed countries (Jablensky, 1992). The improved outcomes could not be fully explained by the higher frequency of acute onset in developing nations and doubts have been raised about the generalizability of findings, based on the theory that a particular type of schizophrenia or a psychogenic psychosis or a delirium-like illness with an underlying medical cause is more prevalent in developing societies (Lin & Kleinman, 1988).

Overall, the 2-year follow-up confirmed the finding from the earlier IPSS study of a better outcome in the developing countries and that type of onset (insidious vs. acute), gender, marital status, and adjustment problems in adolescence are significant predictors of future course and outcome. However, two new predictors of significance were discovered; type of setting (developed vs. developing country) and less social isolation as indicated by frequency of contacts

outside of the family (e.g. close and casual friends) are of equal importance as a predictor of outcome as is the frequency of contact with family members.

Examinations over the long-term (greater than 5 years), however, found that rates of chronic disability are about the same (30%) in developing and industrialized nations. Shortcomings of this study include differential attrition rates between the sites (the highest rates were in the industrialized nations leaving the possibility that those lost to attrition were higher functioning and no longer receiving treatment, other possible explanations may be that these individuals had a worse outcome and were no longer receiving treatment or that they died); a lack of criteria to describe developing vs. developed cultures (some of the developing areas were high-density urban areas); and a lack of data on the availability of modern treatments. Furthermore, the centers in the U.S. were highly heterogeneous in terms of cultural and racial composition (Edgerton & Cohen, 1994). Much more research is needed to sort out the cultural influences from the biological influences. However, the findings of a better course cannot be disputed entirely and an examination of the factors that may be influential is worthy of attention. A summary of variables associated with outcomes are listed in Table 1.

Table 1. Variables associated with schizophrenia outcomes.

.Predictive Variable	Good Outcome	Poor Outcome
Florid psychotic episode at treatment entry		x
Long duration of 1st hospitalization		x
Positive pharmacotherapeutic response	x	
Affective symptoms	x	
Married	x	
Good premorbid functioning	x	
Insidious onset		x
Female gender	x	
Non-Western setting	x	
Urban setting		x
Social isolation		x
Symptom severity		x
Negative symptoms		x
Rehabilitation	x	

b. Social Influences

In both the IPSS and DOSMD studies, social isolation was identified as a factor predictive of a poorer outcome in schizophrenia. The differences between developed and developing nations can be examined in terms of their overall sociocultural attitudes. Western societies are identified as being egocentric where relationships are bilaterally defined, contractual in nature and subject to repeated reevaluations. Individualism, self-reliance, and competitiveness, along with frequent life changes found in modern societies are difficult for patients diagnosed with schizophrenia who function better in situations of stability and predictability. Because the family structure in Western societies is based on the nuclear unit, the caretaker burden to the family is significantly higher, leading to higher EE environments. A high EE environment, characterized by family members who are highly critical or emotionally over-involved in the patient's life, has been shown to have detrimental effects on the course of schizophrenia (Leff et al, 1987). Thus, persons living in the Western world are more susceptible

to being isolated and alone, with a greater loss of social support following each decompensation and/or hospitalization.

In contrast, non-Western societies are identified as being sociocentric with a primary emphasis on social relations that are guided by rules, conventions, and social roles that are sustained in the long-term. Family structure is based on the extended family unit, thereby providing greater support and reduced risk of care taker burden and high EE response. Social support is nearly guaranteed for the patient living in a developing nation, regardless of the course of their illness (Lin & Kleinman, 1988).

Another factor is cultural concepts of mental illness. For instance, in Western cultures psychotic symptoms are viewed entirely as deficits and limitations and generally viewed with pessimism about the future, creating the conditions for hopelessness, stigma and alienation. This is turn fosters a chronic sick role in which the individual becomes trapped. In non-Western nations, the development of meaning around the symptoms of psychosis, a greater acceptance of unusual experiences results in less stigma and allows for more flexible roles within the social system (Anders, 2003; Lin & Kleinman, 1988). Social roles tend to be more accommodating and social support structures more permanent.

Waxler (1977) does not wholly accept the thesis that tolerance and accommodation are the factors responsible for better outcomes in developing societies, but proposes instead that it is the societal expectations of the mentally ill member that determines the outcome. This argument is based on the social labeling theory that postulates that the ways in which a society process and socialize the mentally ill individual into culturally acceptable roles determines whether the illness course will be characterized by chronicity or a return to normality. In many

traditional societies mental illness, considered to be a minor life crisis, is expected to be brief and easily cured. The individual is understood to have remained basically unchanged and the proper treatments, in which the extended family and community participate, are believed to effect cure. This is contrary to the message of chronicity often conveyed in western societies, in which the individual's life becomes defined by role loss, reduced expectations, stigma, isolation/segregation and a grim prognosis of enduring impairment. The individual in industrialized nations is considered to have been transformed, with no evidence of the 'self' that existed prior to the first break. Family members engage only in a supportive role with peripheral involvement in treatment. This often results in a 'impaired role' in which the person is assumed to be permanently disabled in some life areas, while behaving normally in other areas. However, because there is no uniform societal response to mental illness, there are wide variations in others' expectations of the ill individual and thus the varied course outcomes found in research reports. Regardless of the argument, it is clear that social forces (support, social expectations, community involvement and acceptance) have a significant role in determining the course of mental illness. An examination of the effects of the social supports on the individual is discussed in the next section.

B. SOCIAL NETWORKS AND SOCIAL SUPPORT

Historically, it was the discipline of anthropology that initiated studies of social structural patterns in an effort to explain cultural differences in individual and group behaviors. These investigations initially explored the traditional "bounded" support relationships defined by kinship, tribe, and village structures as the elements of community. But these structures proved to be inadequate to explain all social behaviors, thereby leading to explorations of broader non-

traditional "un-bounded" and less socially defined relationships. The study of social networks evolved to function as an analysis of "ties that cut across traditional kinship, residential, and class group" (Barnes and Bott, quoted in Berkman and Glass, 2001).

These insights gave rise to the Social Network Theory in the 1950's and became the focus of attention of many disciplines. Social Network Analysis expanded to encompass the study of network patterns within the collective social system, as well as the network of the individual. This theory was developed as a way of improving the analysis of the structure of different social groups (Hirschberg, 1988). The characteristics of the network structure examined included the 1) size (number of social supports), 2) density or embeddedness (number of network members connectedness to one another), 3) boundedness (type of group structure – neighborhood, family, and work), and 4) homogeneity (similarity of members to one another).

Social Network Theory proposes that the structural arrangement of social organization defines the resources available to each individual and therefore shapes behavioral and emotional responses. An eventual shift was made to an emphasis on the study of personal networks concentrating on the structure of the social relations of the individual involved. Sociologists developed the "egocentric network" approach with a closer inquiry into the structure and function of networks that are assessed from the individual's perspective (Berkman and Glass, 2001).

To provide evidence for this, additional measurements of the social network were incorporated into the analysis of network structures and included an examination of individual ties within the network. These measurements include: 1) frequency of contact with members, 2) multiplexity (the number of different types of connections), 3) duration (how long network

members have been known to each other), and 4) reciprocity (support exchange between the individuals) (Berkman & Glass, 1999).

As this broader understanding of social network structure was examined, an appreciation of the importance of these extended social structures, (extending beyond the limits of previously understood definitions of "community" to a variety of relationship categories) and the influence these structures of social support have on social and health outcomes became apparent (Turner and Marino, 1994).

1. Social Support and Schizophrenia

Considerable evidence has been presented about the overall positive effects of social support on mental health outcomes. Social support has been shown to improve self-esteem, enhance mood, create a sense of belonging and meaning, and as a buffer against stress (Buchanan, 1995). Yet this large body of evidence suggesting an association with overall health and well being has not been entirely successful at identifying the specific aspects of support that promote better outcomes.

The majority of studies have focused primarily on the measurement of the existence of support – the identification of others involved in the individual's life, the frequency of that involvement, and the nature of the involvement. Less attention has been given to the manner in which the support is given. Evidence has emerged that receptiveness to support is dependent on the individual's needs and perceptions of that support. The Behavioral-Ecological Model of social support follows the theory that with "increasing network size, the potential benefits and the potential costs increase simultaneously" (Jeger, 1982); this may be particularly true for

persons diagnosed with schizophrenia. It is well established that the social support structures of severely mentally ill persons are smaller and less dense when compared to those with no mental illness (Lehmann, 1982). As a rule, social integration of people with chronic and serious mental illness is not easy and is even more difficult for persons with schizophrenia, who tend to avoid normative social interactions (Lutfiyya, 1988). One adaptational outcome is that of social withdrawal, often assumed by individuals for whom the demands of the support outweigh the benefits. Individuals diagnosed with schizophrenia frequently acquire this pattern of coping when high emotional stakes are involved (Corin & Lauzon, 1992).

Moreover, not all social support is equally beneficial and there is evidence that support can be detrimental to recovery, as with environments of high expressed emotion. Studies of family environments have demonstrated poorer outcomes in schizophrenic patients residing in high EE households have been well established. These studies have shown that patients living in a high EE environment have a three to four times greater risk of relapse than do patients living in low EE environments (Brown, 1962; Vaughn, 1976; Hogarty et al., 1988; Leff, et. al. 1987). Recent studies have replicated these finding of poorer outcomes when services are provided by high EE mental health staff (Van Humbeeck, 2001; Hansen et al, 1991; Tattan, 2001; Ball et al, 1992, Barrowclough, 2001).

Other studies have focused on the positive aspects of social support. Joyce (1990) conducted a study that examined community adaptation from the perspective of the patient with schizophrenia and found that friends were identified as the most important factor in preventing rehospitalization. Other factors identified as positive influences to community tenure were related to keeping active, developing a healthy lifestyle, a positive self-image, and an acceptance

of the illness. Self-help groups and mental health staff support were found to be the least helpful.

In mental health research, the specifics of social support are by and large examined using the following categories: 1) social embeddedness (the connection the individual has to his social environment), 2) enacted support (actions of others in rendering support) and 3) perceived social support (the support the individual believes is available). Other elements of social support that have also been examined in research include: 1) emotional (love, caring, understanding, empathy), 2) instrumental (assistance with tangible needs), 3) appraisal (feedback, help with decision making), and 4) informational (advice and information giving. Current studies, however, have shown that the usual tools of measurement may not accurately capture the total picture.

A recent study examining the judgments of quality of life and social integration between mental health providers and psychiatrically disabled individuals found congruence in clinical areas, but statistically significant differences in areas of social support. The mean scores on occupational and social relations rated by the provider were lower than the self-ratings of the patients. The researchers considered that this might be due to the fact that the patient is more aware of the supportive nature of individuals identified as social supports (Sainfort, et al., 1996). It may also be that providers are unaware of sources of support their patient may value that do not fit the usual criteria.

Another recent study examining the quality of life of patients who were returned to the community after extended institutionalization found the majority of subjects received most of their emotional and practical support from paid staff rather than from family members or friends.

This study also found that the existence of large social networks did not necessarily mean diminished feelings of loneliness as compared to patients with smaller networks. Quality of life was most dependent on meaningful leisure activities and positive relationships with the neighborhood and greater community; the severity of symptoms and level of functioning played a much smaller role in determining self-perceived quality of life (Borge, 1999).

2. Social Integration, Social Capital, and Schizophrenia

Community integration for persons with psychiatric disabilities has been the goal of governmental agencies and social scientists since the launch of deinstitutionalization. The intention of the deinstitutionalization movement was to relocate severely and mentally ill persons from the confines and limitations of segregated institutionalized care to the broader society where opportunities for full and unrestricted access to community resources are available, including social opportunities. Operational integration involves the physical presence of psychiatrically disabled individuals back to the community from long-term institutional care and has been the primary focus of most post-deinstitutionalization research. The majority of these studies has evaluated integration using the operational definitions of social integration (whether the individual remains in the community, their network size, number of hospitalizations, etc.), yet have not examined the social and psychological aspects of community integration. More research attention is needed to define and measure these aspects of community integration (Wang &Solomon, 2002).

The examination of the impact of social relationships and the social environment has a solid tradition, yet a renewed look at what aspects of these influences are measured may provide better insights (Howe, 2002). Social capital is examined both as community and an individual

resource. At the community level, social capital provides social resources through personal networks that have a shared value and a tendency toward members helping one another (Putman, 1996). At the individual level, it is "the aggregate of the actual or potential resources which are linked to possession of a durable network of a more or less instituionalised relationships of mutual acquaintance and recognition" (Bourdieu as quoted in Baum, 2003). Social capital has become a current area of focus to help explain between group differences in health outcomes and reflects a return of the use of the ecological approach in examining differences in health outcomes versus the examination of individual risk factors. The benefits of social capital are derived from the trust, reciprocity, information, and cooperation associated with social networks and is based on individual-level decisions to participant in community-level activities for the collective manifestations of social capital cannot be sustained in the absence of individual attitudes of trust, reciprocity, and cooperation as well as participation in collective activities (McKenzie, 2003).

Social capital can be horizontal and vertical. Horizontal social capital describes social networks and the associated norms that effect community well-being. Horizontal capital is needed for a community to have a sense of identity and a common purpose and serves as a link to various social groups (religious, ethnic, SES). Vertical capital involves linkage to other individuals that goes beyond demographic boundaries. When vertical links are strong, feelings of responsibility to all members are promoted and serve to decrease social inequalities (Baum, 2003). Conversely, when vertical links are weak, social inequality and the unbalanced distribution of goods prevails, leading to reduced member satisfaction, poorer health outcomes, increased conflicts between groups, and more inequality (Sartorius, 2003).

Individuals with a minimal social capital (vertical and horizontal) have a greater risk of becoming ill, a longer recovery period or a lower likelihood of recovery and also suffer debilitating consequences in other areas of their lives, such as an inability to regain employment (Pevalin, 2003). Evidence has demonstrated consistently that individuals who have strong relationships and who reside within well-integrated communities are less susceptible to illness. For instance, the "Roseto effect" was coined following a mid 20th century study of heart attack rates between four proximal communities that had no significant differences in health behaviors (e.g. fat intake, smoking rates, and exercise), yet one community had a 50% lower incidence of heart attack rates. The difference identified in this community was the close-knit social relationships, family values, and intra-ethnic marriages (Hawe, 2000). The idea of social capital is very similar to the idea of a well-integrated community (Sartorius, 2003).

Social capital increases the likelihood of access to various forms of social support during times of need (Kawachi, 1999). The impact that social capital has on mental health is through the provision of support to mentally ill community members beyond that offered by treatment facilities. In areas where social capital is strong, not only will treatment services be a fiscal priority and therefore readily available to all in need, support by other individuals outside the immediate social network of the mentally ill individual will exist, including employers, extended family, neighbors, and businesses. Further, this support extends beyond social influences to include laws that promote community integration, as well as socio-cultural factors that promote the reduction of stigma (Sartorius, 2003). While the measurement of vocational and social intervention outcomes in mental health research has focused on clinical characteristics and physical integration; the inclusion of cognitive social capital (norms, values, attitudes, beliefs) as

a focus has implications for benefit to all members of the social group (Cullen & Whiteford, 2001).

III. DISTAL SUPPORT

The term distal support is applied to the casual relationships which are the focus of this study; relationships that are not central to the individual's life nor a part of the individual's formal support structure. Merriam Webster (2002) defines distal as being "situated away from the point of attachment or origin or a central point". It seems fitting, therefore, that the term distal support be given to the casual relationships formed through routine interactions.

One can argue that distal support is an example of social capital. It is the support provided through casual community relationships developed as a result of day-to-day encounters with other individuals who live and work in the same community. This support comes from shop owners and sales clerks, wait staff, bartenders, librarians, neighbors, religious professionals, and other community members and are characterized by familiarity, acceptance, and nominal social involvement. These are relationships that most everyone fosters to some degree, but are little thought about. Very often distal relationships involve not much more than a greeting and brief social exchanges. In some instances they are more helping in nature – a willingness on the part of a shop owner to trust that payment will be made later if the purchaser finds that s/he hasn't enough cash on hand to complete the transaction, a drink or food on the house, or words of encouragement and concern. These "weak ties" help to promote a sense of integration and

belonging. For the patient diagnosed with schizophrenia, distal relationships may have a significant influence on successful community tenure.

The initial recognition of significance of "weak ties" came from the classic study conducted by Granovetter (1973). This study revealed the importance of "weak ties" as vital to the social environment of individuals. These ties provide an opportunity to expand social, vocational and other opportunities and function as a bridge to groups and persons with whom the individual may not otherwise have an opportunity to interact. He characterizes these relationships as generally being unequal, with one member of a higher status, or with a different perception of the relationship, than the other. Distal supports are weak ties that provide intangible support of acceptance, familiarity and sociability through routine encounters in a predictable environment without imposing emotional demands or requiring reciprocity.

The study conducted by Cohen and Sokolovsky (1978) was one of the earliest studies with findings that suggested that relationships for individuals diagnosed with schizophrenia are characterized by limited social involvement. This was a study of social interactions in New York City involving patients diagnosed with schizophrenia who resided in a single room occupancy hotel (SRO) that was an experimental residence occupied by indigent individuals in need of supportive services, 95% of whom were diagnosed with schizophrenia. The remaining residents had various other psychosocial problems, particularly alcoholism. The majority of residents were permanent, but nightly rentals were also available. Located within the hotel was a multi-agency social service office connected to a lounge open to all residents, thereby providing a space for social interaction among the residents. The researchers used participant observation, daily records of activities, thorough biographical interviews, and a network profile instrument to

measure the density, mutiplexity, and directionality (instrumentality, reciprocity, and dependency) of the networks of randomly selected tenants (one-quarter of the total SRO population, N= 44) who fell into three categories: tenants with mild to severe residual symptoms; tenants with minimal or no residual symptoms; and tenants with no psychotic history. Relationships both within and outside the SRO were examined, professional relationships were not included.

In terms of network size within the SRO, significant differences were found between the groups. The smallest number of relationships was among those with moderate to severe symptoms and gradually increased to the highest among those with no psychotic history. This trend, although not statistically significant, was also found in terms of the multiplexity of the relationships. In terms of directionality in relationships, both groups diagnosed with schizophrenia had significantly fewer instrumental relationships, but also had the most dependent relationships, within and outside the SRO, than the non-psychotic group. In terms of the degree or density of relationships (defined in this study as the average number of relations each person has with others in the same network), the participants with moderate to severe symptoms had networks that were much less dense than in either of the other two groups, thereby indicating a lower social investment within each relationship. This study did provide support for the idea that patients with schizophrenia tend to isolate, yet even among the most severely symptomatic patients social relationships were maintained both within and outside the SRO despite the fact that a lower density of social involvement characterized these relationships.

Several studies have presented evidence of the benefit of distal relationships on outcomes in schizophrenic patients. A discussion of these studies follows. A summary can be found in Table 3 at the end of this section.

Lehmann (1983) conducted two studies of individuals residing in SRO's. The first involved three SROs; one with a predominantly psychiatric population of discharged patients of long-stay facilities, the second with a predominantly geriatric population, few of whom had psychiatric histories; and the third with tenants who were primarily in their middle years, one-quarter of whom had a psychiatric history. The purpose was to examine the relationship between social support and well being among residents who had a psychiatric history as compared with those who do not. Social contacts within and outside the hotel were recorded for each participant, in addition to an instrument that assessed the individual's perception of the social environment within the hotel, as well as a life satisfaction measure. Relationships between actual social contacts within the SRO and life satisfaction were found to be strongest among the non-psychiatric residents, yet the relationship between the perception of social contacts within the SRO and satisfaction was strongest for the psychiatric population. Interestingly, the social contacts outside of the hotel (primarily family) were often reported to be harmful by the tenants with a psychiatric history.

More in-depth inquiry with the patients led the researchers to conclude that the characteristically superficial and undemanding nature of the contacts within the SRO were preferable to the more intense relationships with contacts outside the SRO, suggesting a preference for a small and on hand network of casual acquaintances. To further explore this finding, a second, more intensive study was conducted in another SRO with tenants primarily

comprised of psychiatric patients. One-quarter of the occupants were randomly selected and given a structured interview to measure both the quality (casual acquaintances to intimate relationships) and extent of their relationships with others. A life satisfaction instrument was administered, functional status was measured, and daily activities were recorded. Analysis concluded that casual social relationships with other residents accounted for a higher satisfaction and improved day-to-day functioning (increased activities such as working on a hobby, reading, participating in group activities), improved self-esteem and sense of well being. Outside supports (friends and relatives) were not found to have an influence on these factors.

That perceptions of social relationships may be different among chronic patients diagnosed with schizophrenia was demonstrated by Leff, et.al (1990) in a study of the social networks of long stay patients in a mental institution that included all patients who were functionally able to complete the Social Network Schedule (489 of 770). All monthly contacts for each participant (mean = 8) were measured in terms of whether the contact was missed during absence, whether each contact was considered to be a friend and/or confidant, and the nature of the interaction (active, intermediate, or passive). The contacts were classified into three categories: 1) contacts whose names and roles are known, but involve only passive exchanges (e.g. greetings), 2) contacts with relationships characterized by an active conversational social exchange, and 3) contacts in which social interactions are intermediate, predominantly non-verbal, and characterized by the exchange of goods and services. The majority of contacts fell into category one, the fewest in category 2. Contacts that fell into categories 2 and 3 had an equally likely probability of being identified as a friend. Furthermore, it was found that contacts in category 1 - contacts with whom social interactions were limited to greetings or non-verbal interactions - were equally likely as category 3 to be identified as

confidants, suggesting this manner of social engagement holds a much greater significance for individuals diagnosed with schizophrenia than for individuals free of a psychotic disorder (Leff, et. al., 1990).

The Montreal study (Corin & Lauzon, 1992; Corin, 1998) found that patients who engaged in casual community relationships had fewer hospitalizations than those who relied solely on social interactions limited to family members and the mental health community. This study was conducted with the goal of understanding the factors involved in the patient's process of building a life in the community after hospitalization. Forty-five randomly selected male patients with comparable clinical profiles were divided into three categories according to rehospitalization history during the prior 4 years; non-rehospitalized patients, those rehospitalized 1-2 times, and those rehospitalized 3 or more times. The researchers report on the findings between those not rehospitalized and the frequently hospitalized groups (n=28). Using intensive structured open-ended questionnaires, social integration was measured on three levels: social roles, social relationships, and relations with family, as well as the patient's perceptions of their family dynamics. Patient's self-perceptions were explored using a narrative style. Additionally, a detailed accounting of each participant's activities and social contacts during the preceding week was recorded, thus allowing a comparison between the patient's perception of their social supports and the actual daily interactions.

Both groups reported few interpersonal relationships within and outside kinship ties, as well as minimal normative social roles (e.g. married, employed). Differences between the two groups, however, were found in their perceptions and expectations of their social position. The frequently hospitalized patients desired more attention from others and felt neglected by family

and friends. They also felt subordinated in their roles with others; relationships were characterized by less reciprocity and more dependency, whereas the non-rehospitalized group saw their role in relationships as neither that of giver nor of receiver. More significance was attached to relationships with family members than with friends in the frequently hospitalized group, in contrast to the non-rehospitalized patients who attached greater significance to relationships with friends. The more frequently hospitalized group sought a normative ideal in terms of social integration, whereas those patients with greater stability in the community were more comfortable in a position withdrawn from the world, what the researchers termed "positive withdrawal", whereby value and significance, often spiritual, was attached to their solitude.

Analysis of the non-rehospitalized patient's daily routines revealed that frequenting local establishments (restaurants, local stores) on a routine basis held great importance in that these activities provided opportunities for relating to others, while allowing a social distance. On the other hand, more frequently hospitalized patients participated in psychiatric programs and services on a routine basis, despite having comparable clinical profiles to the participants who had fewer mental health contacts. The frequently hospitalized patients aspired to more normative roles within society and felt inadequate, believing that they were failures for not reaching these goals yet feeling no hope that they would. The non-rehospitalized patients were not as concerned with normative roles and did not feel pressured by societal expectations. They recognized that they did not fit the cultural ideal, yet remained confident in their withdrawn lifestyle. Although the effects of stigmatization was felt negatively by both groups, the frequently hospitalized patients felt entirely trapped by this, whereas the non-rehospitalized patients were less concerned about what others thought of them. The frequently hospitalized

patients felt static within the sick role and the non-rehospitalized patients saw their position as dynamic, with a promise of a more integrated future.

Beal (1997, 1999) interviewed nine individuals diagnosed with schizophrenia and 22 of their identified friends using the grounded theory approach (a technique in which theory is generated and tested as part of the data gathering process, analysis begins with the first interview) and a semi-structured interview with the goal of discovering the relationship-building process for patients diagnosed with schizophrenia who reside in the community. All the patients were of the same socioeconomic background and experienced varying degrees of residual symptoms as measured by the general assessment of functioning scale (GAF). The interview inquired about how participants spent their days, individuals they saw on a regular basis, and how they would describe each relationship. Friends identified included neighbors, relatives, and persons met in the community. The interviews revealed that the participant's days involved routines providing opportunities for regular social interactions that were superficial and predictable, often with minimal conversational exchange, and low on emotional demands. All of the participants said that their daily routine involved talking with people in public places such as the street, retail establishments, or restaurants. Many of the friends identified were people they encountered regularly in the community. For instance, one participant identified a priest as her friend although they never held a conversation. Another participant identified the owner of a laundromat she frequented. Additionally, all participants emphasized their need for solitude and identified as a requirement of a friendship the ability to easily end an interaction when they chose and a preference for relationships that were kept "in the background" of their lives. The act of greeting people on a daily basis helped to develop a sense of community and connection. The regular encounters of their daily routines offered the opportunity for safe interactions in

predictable situations in which limited emotional demands were made. Even though the ties that were identified were weak in terms of emotional and even cognitive intimacy, they did provide continuity and a feeling of being cared about. In summary, this study concluded that community integration of individuals with schizophrenia consisted of the "weak ties" of regular encounters; encounters that were meaningful to the individuals, even when they involved minimal social exchange. The size of the network has not been found to be of important for community integration, but the day-to-day interactions that define it. These relationships, relationships that may appear unimportant to the observer, were regarded as rewarding and supportive. The habitual routines in the community provided participants with safe interactive opportunities for developing social competency. Most of the studies measuring social support rely entirely on the reported number of family and friends, without exploring more carefully the nature of these relationships, how they are perceived, and whether they are actually supportive or rejecting. What makes social integration possible is the process of sociability under various conditions where normative expectations can come to be understood and adapted to on a level tolerable to the individual diagnosed with schizophrenia, not something that is taught and learned (Beal, 1996). The understanding that learning to be sociable with people encountered regularly at restaurants, libraries, and at local stores, where predictability and brevity of exchange can provide a sense of integration without intrusion or affective involvement, has implications for future intervention strategies.

As outlined earlier, studies have shown that individuals diagnosed with schizophrenia in urban industrialized areas have poorer outcomes than patients in rural industrialized areas and individuals in industrialized countries have poorer outcomes than patients in developing countries. One of the postulated reasons for these differences in outcomes is the availability of

wider community social network that provides a sense of belonging and acceptance. It may be that individuals diagnosed with schizophrenia in industrialized urban areas who develop a network of distal support have created an environment that promotes a niche characterized by acceptance and belonging, making available social connections through weak ties, but allowing for a distance from social roles and social relationships. Studies to date of this phenomenon have been few.

Table 2. Summary of studies examining casual support.

Study Design	Researcher	Population	Finding	Weakness
Longitudinal participant observational and survey study of randomly selected tenants of an SRO. Compared social network measures among three comparison groups: 1. Residents with mild to severe residual symptoms of schizophrenia, 2. Minimal or no residual symptoms, 3. No psychotic history.	Cohen & Sokolovsky, 1978	Individuals residing in an SRO, 95% diagnosed with schizophrenia, remaining with substance abuse problems.	Residents diagnosed with schizophrenia have significantly fewer contacts, but even the most impaired were not totally isolated. Small, nonmultiplex networks are correlated with frequent rehospitalizations Residents with minimal residual deficits were strong members of the hotel community.	Measured only social networks of participants. Lacked examination of other clinical and sociocultural variables.
Study 1. Cross sectional survey comparing the social networks, life satisfaction, and sense of well-being among three SRO's with different resident profiles (predominantly psychiatric, predominantly geriatric, predominantly non-psychiatric, and middle aged with ¼ psychiatric). No measures of functioning.	Lehmann, S, 1982	Tenants of 3 SRO's with and without psychiatric histories. Specific diagnoses of those with psychiatric history not reported, nor was the participation rate.	Found a preference for small, local network of casual acquaintances as provided in the SRO. Low incidence of rehospitalization, enhanced subjective well-being and life satisfaction found in psychiatric participants.	Lack of uniform clinical criteria for sample population.
Study 2. Cross sectional survey examining social networks and relationship quality, life satisfaction, level of functioning, as well as participation in activities both within and outside the SRO.	Lehmann, S, 1982	Tenants residing in an SRO inhabited by older individuals with psychiatric history. Three quarters of the residents were surveyed.	Confirmed that casual, low-intensity relationships were associated with better outcomes than intense relationships. Twenty-seven and 29% of variance in life satisfaction and well-being, respectively, explained by the presence of casual conversational opportunities.	Lack of uniform clinical criteria for sample population.

Table 2. Continued

Study Design	Researcher	Population	Finding	Weakness
Cross sectional study examining the frequency of contact, the nature of the interaction, and the perception of the relationship (e.g. friend, confidant) with others	Leff et al., 1990	All patients in a long stay mental institution who were able to functionally able to complete a social network instrument..	Casual contacts involving minimal social exchange were often identified as confidants and friends.	Sample population was not community based. Lack of uniform clinical criteria for sample population.
Qualitative and quantitative research using anthropological and psychiatric phenomenology methods. Data on behavior, subjective perceptions and expectations, and social and family network were collected strictly from the patient's perspective to examine social integration by open-ended semi-structured interview.	Corin & Lauzon, 1992	Random selection of men diagnosed with schizophrenia receiving outpatient care. Participants were categorized according to their utilization of psychiatric services.	Daily routines of participants who were less reliant on mental health services involved frequenting local establishments where positive opportunities for relating to others at a social distance, termed 'positive withdrawal' by the researchers.	Small sample size. Lacked standardized measurements of participant characteristics (e.g. life satisfaction, formal social network structure) to compare participant groups.
Qualitative research using the grounded theory design with a semi-structured interview.	Beal G., 1997	Random selection of individuals with a diagnosis of schizophrenia and 22 of their identified friends residing in a specific geographical area to control for SES.	The "weak ties" formed by day-to-day encounters with other community members were found to a positive impact on a sense of community and connectedness, as well as a sense of being cared about. These relationships provided an opportunity for a safe interactive environment with minimal emotional demands.	Small sample size. Lacked standardized measurements of participant characteristics (e.g. life satisfaction, formal social network structure).

IV. OBJECTIVES

Interest in social network analysis has steadily grown in the past few decades with the majority of studies focusing on the structure (e.g. friends, relatives, professional support) and function (e.g. instrumental, emotional) of social networks. Only a few studies have examined the benefits of distal support to community integration and successful tenure (Corin & Lauzon, 1992; Beal, 1999). Findings of these studies revealed that casual relationships with community members held significance for individuals diagnosed with schizophrenia, provided opportunities for sociability, and created a sense of community. Furthermore, patients who developed distal relationships were less reliant on mental health services and had a greater satisfaction with their lives. However, these studies were qualitative exploratory studies with small sample sizes.

This study will use an instrument designed specifically to measure distal support sources found in the community for each participant. The association of distal support with measures of functional status, quality of life, and personality factors will be assessed.

Specifically, the objectives of this study are listed below:

1. To develop a measure of distal support.
2. To identify clinical and sociodemographic factors that are associated with the degree of distal support received in the community. It is predicted that the presence of distal supports will correlate positively with higher scores on the extraversion, openness, and agreeableness factors and lower scores on the neurotic factor of the NEO-FFI.

Higher functional characteristics will correlate positively with the number of distal supports.

3. To measure the association between distal support and life satisfaction and sense of belonging. It is predicted that distal community support will correlate positively with greater life satisfaction and a higher sense of belonging scores.
4. To collect data on the number of community inpatient, emergency room, and outpatient services during the previous three years. It is predicted that participants with distal community supports will have fewer contacts with these mental health services.

V. METHODS

A. STUDY POPULATION

Patients were included in the study if they have had a DSM-IV diagnosis of schizophrenia or schizoaffective disorder for three or more years, were between the ages of 21 and 65 years, and had continuous enrollment at WPIC-UPMC services during the previous 3 years. Measuring the mental health service use over the course of the previous three years provided data that reveals each participants average need for professional support. A shorter time frame would not have allowed this due to the fluctuating course of schizophrenia and consequent variability in service utilization. A longer time frame made the criteria too restrictive for recruitment feasibility. Patients were excluded if they were unable to negotiate the community independently (e.g. use of public transportation, attend appointments without assistance).

Table 3. Eligibility and Exclusion Criteria

Eligibility Criteria	Exclusion Criteria
1. Participants must be between the ages of 21 and 65. 2. Participants must have a stable diagnosis of schizophrenia or schizoaffective disorder during the previous three years. 3. Participants must have received continuous treatment at WPIC for the three years prior to the study.	1. Individuals who are unable to negotiate community movement independently (e.g. use public transportation, shop independently)

B. STUDY SITE

All patients who participated were receiving treatment in the Comprehensive Care Services (CCS) clinic. CCS is an outpatient clinic of the Western Psychiatric Institute and Clinic of the University of Pittsburgh Medical Center System (WPIC-UPMCS) that provides ambulatory treatment to severely mentally ill patients. Two levels of care are offered: 1) the outpatient program offers individual therapy, family interventions, and medication management and involves fewer contacts with providers and 2) the adult partial hospital program, an intensive treatment program providing individual and group therapy, family therapy, medication management, psychoeducation and rehabilitation services and more frequent contact. This is generally offered on a shorter-term basis as an alternative to hospitalization or as step-down from hospitalization for individuals needing more intensive interventions. Dual-diagnosis (e.g. schizophrenia and alcohol dependence) group therapy and rehabilitative services (vocational counseling, skills development, math and reading, volunteer opportunities, etc) are available to all patients enrolled in the CCS clinic. Participants were recruited from both levels of treatment.

Case management services are also offered at UPMC-WPIC. These services are community based and have three levels of care: Resource Coordination (RC) offers a "brokerage" service whereby the case manager's role is to identify needed services and link the client to those services by overseeing the referral process. Contact is required only once per month. Intensive Case Management (ICM) also provides the brokerage service, but is a more comprehensive service whereby the case manager has more frequent contact in the community, involving home visits and often accompanies the client to medical and other (e.g. recreational) appointments. Continuous Treatment Team is the most comprehensive and is reserved for clients who have frequent hospitalizations or who have difficulty participating in traditional treatment. Each team consists of a nurse, a psychiatrist, and a case manager who provide comprehensive treatment to the client in the community.

Both the UPMC-HS WPIC Research Committee and the Institutional Review Board (IRB) of the University of Pittsburgh granted approval for the study.

C. RECRUITMENT

1. Pilot Study

The director of the CCS clinic discussed the study with eligible patients from his caseload. If the patient granted permission, telephone contact was made with the patient and the study was thoroughly described. If interest remained, an interview was scheduled. Participants read and signed the consent form and questions were answered before beginning the interview. Each participant was paid $25.00 in cash for participating.

2. Full Study

Subjects were recruited using three recruitment strategies. First, a flyer was posted on the clinic premises with a brief description of the study and a list of the eligibility criteria. A phone number was supplied for individuals to initiate participation. Upon receiving a call from interested individuals, their age, diagnosis, and duration of treatment with WPIC were elicited to screen for eligibility. Individuals were considered to be ineligible if they did not meet the age restriction (21-65), reported an ineligible diagnosis (bipolar disorder, psychotic depression, or unknown), or were not in treatment exclusively at WPIC during the previous 3 years. If the individual reported criteria that made them eligible for the study, an interview was scheduled.

Secondly, referrals were sought from treating clinicians and psychiatrists. Detailed information about the study was provided in a weekly staff meeting and consent documents for permission to contact were distributed. Treatment professionals could either suggest that the patient make contact independently or provide the patient's information after gaining written consent.

Thirdly, interviews were scheduled on site at the clinic with patients who were informed of the study by their clinicians during scheduled clinic appointments.

Interviews were conducted in an office at the clinic. Participants read and signed the consent form and all questions were answered before the interview began. Eligibility was verified by a review of Clinical Progress Notes (CPN) after the patient signed written consent and the interview was completed.

D. MEASUREMENT INSTRUMENTS

Data were collected by the administration of the instruments and by Clinical Progress Notes (CPN) review. Table 2 outlines the method of collection according to each data item. This is followed by a description of each of the instruments employed in the full study. Changes in the instruments used are discussed in the Section VI.

Table 4. Data collection methods.

Data	Instrument	Collection Method
Personality Factors	NEO-FFI	Researcher administered
Activities & Role Performance	CIQ	Researcher administered
Quality of Life	LQoLI	Researcher administered
Global Functioning	GAF	Researcher rated
Symptom profile	SRS	Researcher rated
Social Network	SNI	Researcher administered
Sense of Belonging	SOBI	Researcher administered
Distal Support	DSM	Researcher administered
Provider Contacts	Medical Records Form	CPN
Diagnosis	Medical Records Form	CPN
Housing status	Medical Records Form	Participant report & CPN
Sociodemographics	Interview	Participant report & CPN
Source of income	Interview	Participant report

1. Clinical Progress Notes

Records were reviewed on each participant via Clinical Progress Notes (CPN), a computerized record-keeping database used by treatment providers in the WPIC system. All staff (psychiatrist, clinicians, case management, outreach) providing services to patients documents each contact in the CPN database. CPN records also provide information on current and past diagnoses (including history and physicals, diagnostic evaluations), numbers of acute care hospitalizations, outpatient services, and emergency room visits during the past three years.

a. Contacts with mental health services

Number of contacts was counted as the total number of CPN notes written during the three years prior to the interview date. Each CPN note is titled to describe the type of service (e.g. group or individual therapy, case management, MD medication management); whether the service was provided in person or by telephone, and whether or not the service involved patient contact (notes written that did not involve patient contact were not counted). It was beyond the resources of this study to review each note in the three year time span (number of notes written ranged from 19 to 1,178) and although a therapy session cannot be equated with a phone call, the research question is to examine each participant's frequency of contact with the mental health system over the course of three years as a measure of reliance on the system. Therefore, a count of notes written without weighing the time involved or the specific nature of involvement (e.g. assisting with benefits, providing phone support, cognitive therapy) was used in this study. Service type was distinguished between CCS outpatient (partial hospitalization and outpatient) and case management services (ICM, RC, or CTT).

Two participants were found not to meet the criteria of 3 years of continuous treatment at WPIC and were not identified until after the consent. The data for these participants was extrapolated to estimate the number of contacts over the course of three years. The number of contacts was estimated for the full three years using the following method of extrapolation: The ratio of the total contacts was divided by the number of months the participant was in treatment and made equal to quantity x divided by 36 (months in three year period) to extrapolate the total number of contacts. Participant 47 was in treatment from 4/16/2002 to 12/29/2003 (the date of study entry) and had and a total of 32 CCS contacts in that 20 month period. The ratio would be

32/20 = x/36 or 20x = (32) (36) = 57.6 contacts in the 36 month period. Participant 62 was in treatment from 4/16/2002 to 3/3/2004 (the date of study entry) and had and a total of 27 CCS contacts in that 23 month period. The ratio would be 27/23 = x/36 or 23x = (36) (27) = 42.3 contacts in the 36 month period.

2. Measures

a. NEO Five-Factor Inventory (NEO-FFI)

This scale is a shortened version of the NEO-PI designed to quickly (10-15 minutes) give reliable and valid measures of the five domains of the personality (neuroticism, extraversion, openness to experience, agreeableness, conscientiousness). Sixty items are rated on a five-point scale. The NEO-FFI scales show correlations of .75 and .89 with the NEO-PI. The NEO-PI has an internal consistency coefficient range from .86 to .95 for the domain scale (Costa & McCrae, 1991). This instrument was researcher administered. Higher scores indicate stronger personality characteristics in each of the domains.

b. Community Integration Questionnaire (CIQ)

This scale consists of 15 items designed to measure home integration, social integration, and productive activities. Scoring is primarily based on the frequency of activity and role performance and whether these are performed independently or with assistance. The overall score can range from 0 to 29; the home integration score can range from 0 to 15; the social integration score can range from 0 to 12; and the productive integration score can range from 0 to 7. A high score indicates greater integration (Willer, B; Sander, 1999). This instrument was researcher administered.

c. Lehman's Quality of Life Interview (LQoLI)

This scale consists of 158 items designed to measure both objective and subjective quality of life in the seriously mentally ill population. The purpose of the interview is to measure the life circumstances of persons both in terms of what they actually do and experience (objective) and their feelings about these experiences (subjective). The objective information is first obtained and is immediately followed by the subjective information using a fixed interval (1-7, Terrible - Delighted) Likert scale. Higher scores indicate greater satisfaction.

Pooled data from studies conducted over 13 years show a reliability coefficient in excess of 80%. Correlation coefficients ranging from .11 to .37 have verified discriminant validity (Lehman AF, 1988). This instrument was researcher administered.

d. Sense of Belonging Instrument (SOBI)

This scale is a 27-item instrument consisting of two separately scored scales using a 4-point Likert-type scale (strongly agree to strongly disagree). The SOBI-P (psychological state) consists of 18 items measure the individual's sense of being valued and sense of fit in interpersonal relationships. The SOBI-P score can have a range from 18 to 72. The SOBI-A (antecedents) consists of 15 items to measure the desire for meaningful relationships and the energy for involvement. The SOBI-A score can have a range from 15 to 60. The total SOBI score can have a range from 33 to 132. Low scores indicate a greater sense of belonging (Hagerty & Williams, 1996). This instrument was researcher administered.

e. Social Network Index (SNI)

This scale measures three aspects of social networks. First it measures network diversity, a measure of the number of high-contact roles. Second it measures the number of people in the social network with whom the respondent has regular contact. Thirdly, it measures the number of embedded networks, a measure of the number of different network domains in which the respondent is active including family, friends, religion, school, work, neighbors and volunteer activities. The network diversity score can have a range from 0-12; the number of people in the network can have a range from 0 – 68; the number of embedded networks can have a range from 0 – 8; and the family score can have range from 0 – 15. High scores indicate a greater number of social supports (Cohen, 1997). This instrument was researcher administered.

f. Schizophrenia Rating Scale (SRS)

The Schizophrenia Rating Scale is the result of work done through the Texas Medication Algorithm Project (TMAP) schizophrenia module. It is a brief 8-item scale, consisting of four items that assess negative symptoms (adopted from the Negative Symptom Assessment (NSA) scale and the Scale for the Assessment of Negative Symptoms (SANS)). The areas of negative symptoms assessed are: 1) Time to response, 2) Facial expression, 3) Hygiene; and 4) Social drive. Four items assess positive symptoms and are adapted from the Brief Psychiatric Rating Scale (BPRS). The areas of positive symptoms assessed are: 1) Suspiciousness, 2) Unusual Thought Content, 3) Hallucinations, and 4). Conceptual Disorganization. This instrument was researcher rated. The total score can range from 0 to 44. Higher scores indicate a higher

symptom profile (Texas Medication Algorithm Project, Texas Department of Health Services). This instrument was researcher rated.

g. Global Assessment of Functioning (GAF)

The purpose of this scale is to assess the overall level at which the individual functions in areas of social, occupational, academic, and other areas of performance expressed in a numeric scale. Functioning impaired by physical and environmental constraints should not be considered. The scale ranges from 1 (persistent danger of hurting self or others, inability to care for self) to 100 (superior functioning) (Diagnostic and Statistical Manual of Mental Disorders, Fourth Ed.). This instrument was researcher rated.

h. Distal Support Measure (DSM)

The Distal Support Measure developed for this study calculates the number of distal relationships each patient has in the community. Data is collected from each participant on the frequency of contact with the distal support, how long they have been frequenting the establishment, whether they look forward to their time there, whether they're recognized, whether they know the names of others there and are known by name, whether they feel welcomed, whether they have received help there, as well as the participant's perception of the relationship (i.e. friend, acquaintance). Each participant is asked about his or her specific interactive experiences (listed below) in the community, first focusing on places where they are likely to frequent on a regular basis (i.e. grocery store, local market, drug store, favorite restaurants/coffee shops) then the participant is asked to identify other places where they spend time on a regular basis. This instrument was researcher administered.

1. Scoring number of distal supports

For an identified potential source of distal support to be considered a distal support, three of the following five must have a positive score:

- Do you look forward to going there?
- Do the people recognize/acknowledge you when you come in?
- Do you know their name?
- Do they know your name?
- Do you consider them to be a friend or an acquaintance?

Summing the number of sources of distal support will create the total number of distal supports.

E. DATA ANALYSIS – PILOT STUDY

1. Content Validity

To examine the content validity of the Distal Support Measure, sources of distal supports identified by the participants in the pilot study were compared to sources identified in previous studies (Corin & Lauzon, 1992; Beal, 1999).

2. Test-Retest Reliability

To examine reliability, the results of the first and second administrations of the Distal Support Measure, conducted approximately 2 weeks apart, were compared by plotting the results of the post test against the pre-test.

3. Redundancy of Measures

To examine any redundancy in the measures, information collected in the instruments were examined to compare the nature of the support the instrument was measuring.

F. DATA ANALYSIS – FULL STUDY

Analysis began by describing the sociodemographic characteristics (e.g. sex, race, etc.) of the participant population. Descriptive statistics, including measures of central tendency (e.g. means, medians) and dispersion (e.g. standard deviations, ranges) will be computed for continuous data. Frequency distributions were estimated for categorical data.

Assumptions were tested by examining normal probability plots of residuals and scatter diagrams of residuals versus predicted residuals. Violations of normality were found with the quality of life satisfaction scores; to correct for this, the scores were ranked for analysis. Violations were also found with mental health contacts; to correct for this, the number of contacts with ambulatory services (all CCS and case management contacts) were logged transformed for analysis. The number of hospitalizations and emergency contacts

were placed in the following categories; no hospitalizations/emergency contacts, one to two hospitalizations/emergency contacts, and three or more hospitalizations/emergency contacts.

1. Power

For all aims the sample size was calculated using the PASS statistical package. With fifty-eight participants there will be 80% power to detect a correlation of .36 at an alpha level of .05 with a two-sided alternative hypothesis.

2. Hypothesis I

In the first hypothesis it was stated that the amount of distal community support will correlate with higher openness, extraversion, and agreeableness scores and lower neuroticism scores on the NEO-FFI, lower symptom profile scores (SRS), and higher functional characteristics (CIQ, GAF).

To test this, nonparametric (Spearman) correlation analyses was used to identify associations between distal support measures and scores on the NEO-FFI, SRS, CIQ, and GAF scales. The possible confounding effects of difference in other characteristics (e.g. gender, housing situation, race, age, etc.) were controlled in the analysis by adding the variable to the linear regression model.

3. Hypothesis II

In the second hypothesis it was stated that the amount of distal community support will correlate positively with greater life satisfaction scores (LQoLI) and higher sense of belonging scores (SOBI).

To test this, nonparametric (Spearman) correlation analysis was used to identify associations between distal support measures and scores on the LQoLI, SOBI, and SNI scales. The possible confounding effects of difference in other characteristics (e.g. gender, housing situation, race, age) were controlled in the analysis by adding the variable to the linear regression models. The number of distal supports was forced into each model to examine the direction and significance of the association

4. Hypothesis III

In the third hypothesis it was stated that measures of distal support will correlate negatively with number of contacts with mental health facilities even when scores on symptom profile and functional status are controlled statistically.

To test this nonparametric (Spearman) correlation analysis was used to identify associations between distal support measures and three year history of acute care hospitalizations, emergency room visits, and utilization of CCS and case management services. ANOVA analysis was used with dichotomous variables (i.e. race, gender, housing). The possible confounding effects of differences in other characteristics (e.g. gender, housing situation, race, age, CIQ, SNI, SRS, and LQoLI, SOBI, GAF, demographic characteristics, housing) were controlled in the analysis by adding the variable to the linear regression (ambulatory services) and logistic regression models (hospitalizations and emergency contacts). The number of distal supports was forced into each model to examine the direction of association and significance of the association

VI. RESULTS

A. PILOT STUDY

The first goal of the pilot study was to determine the feasibility of identifying and recruiting eligible participants. The second goal of the pilot study was to determine the appropriateness of the selected instruments and to identify any redundancy of measures between the instruments. The third goal was to test the Distal Support Measure.

1. Feasibility of Recruitment

A total of nine referrals were made. Of those, one individual refused participation, another scheduled to meet a number of times but failed to keep any appointment, another could not schedule until after the recruitment period ended, and 2 completed only the first of two interviews. The pilot study included a total of four participants.

Table 5. Recruitment history pilot sample.

Referral	Outcome
Referral One	Completed both interviews.
Referral Two	Initially agreed, but canceled repeatedly.
Referral Three	Did not consent.
Referral Four	Completed both interviews
Referral Five	Completed pre-interview only
Referral Six	Completed pre-interview only
Referral Seven	Completed both interview.
Referral Eight	Completed both interviews.
Referral Nine	Agreed, but past end of recruitment period

The greatest impediment to participant recruitment was the requirement of 5 year of continuous treatment at UPMC-WPIC. The eligibility criterion is not otherwise restrictive as a deliberate means of recruiting a wide cross section of individuals in terms of illness severity and psychosocial circumstances. All participants were asked to give their thoughts about the interview. None stated that it was too long. All agreed that it was not a difficult interview and three stated that they found it to be interesting.

2. Participation.

Table 6 shows descriptive statistics of the pilot sample. There were four participants, half were male and three were black with an age range from 32-52. Two were diagnosed with Schizoaffective Disorder and two with Chronic Paranoid Schizophrenia.

Three of the four participants were living independently in the community in private apartments. One of these three was only recently making the transition from the parental home. One lived in a supported housing apartment building where he had a private apartment,

but with staff on-site 24 hours a day. All participants were high school graduates and completed at least one year of post secondary study. One participant attended several colleges, but did not complete the requirements for a college degree. All participants were unemployed; two were seeking employment.

Table 6. Pilot study participant characteristics.

Characteristic	N
Race	
Black	3
White	1
Gender	
Male	2
Female	2
Ages	32, 37, 39, 52
Diagnosis	
Schizoaffective disorder	2
Chronic Paranoid Schizophrenia	2
Marital Status	
Separated	1
Never married	3
Years of School	13, 13, 16, 17
Current living situation	
Supported housing – 24 hour staff	1
Private apartment – living alone	3
Employment status	
Unemployed	4

B. DISTAL SUPPORT MEASURE

1. Content Validity

The questions developed for this questionnaire were principally based upon the concepts and findings presented in studies conducted by Corin & Lauzon (1992) and Beal (1999), as well as from extensive experience gained by this researcher while working in the community with this patient population. Input was provided throughout the development process from the committee

member to further develop and improve the questions. Data gathered in the pilot study did yield sources of distal support consistent with the findings of the above studies. For instance, one respondent related that the owner of the convenience store where she regularly shops often gives her salads or sandwiches and will give her a pack of cigarettes on credit when she is out of money. Another respondent reported that he frequently receives support during anxiety attacks, as well as answers to his questions, from the staff in the library where he studies regularly.

2. Test-Retest Reliability

Figure 1 illustrates the change in total distal support scores of the post interview against the pre interview. All but one of the participants increased their total number of distal supports and frequency of contact on the post-test. One participant increased his score from none to five distal supports, another increased from one to four distal supports, a third increased from two to three and the fourth reduced his score from three to one distal support.

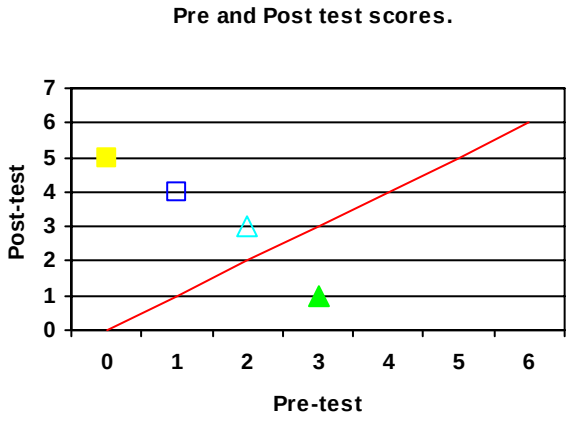

Figure 1. Pre and Post Test Scores on Distal Support Measure.

This finding indicates that an understanding of the research question was improved from the first to the second interview, therefore a more thorough introduction, with examples was needed

Results of the analysis of the comparison between the pre and post test scores reveal that the Distal Support Measure had low reliability in its initial form. Changes were made to improve reliability for the collection of data in the full study. These changes are detailed in the Distal Support Revisions section.

3. Redundancy of Study Measures

Although four of the six instruments measure social relationships, each has a distinctive focus. The LQoLI and SNI instruments both inquire about the nature of the relationship (e.g. family, friend, community organization) yet with different concentrations; the LQoLI interview adds an aspect of intent (i.e. scheduled get togethers) and manner of social involvement (e.g. written correspondence, romantic), as well as subjective and objective quality of life scores relating to social relationships; the Social Network Index examines the number and frequency of contacts in order to measure the diversity, embeddedness, and size of the social network. The Community Integration Questionnaire examines the extent to which the participant engages in activities independently in the community involving skills of daily living, as well as social participation and the degree of assistance received to complete/participate in the activities. The Distal Support Measure is designed to examine only casual community relationships.

The LQoLI, SNI, and CIQ each have questions relating to employment status and school enrollment. The LQoLI includes more in-depth questions about the participant's employment

status (e.g. length of time employed or unemployed, length of time in school, satisfaction with employment status or school functioning, whether seeking employment in the case of unemployment and whether applications for employment have been submitted, etc.). The SNI and CIQ instruments only gather data on current employment status or school enrollment. Table 7 summarizes these findings.

Each of these instruments provides unique information pertinent to this study. Redundancy of some questions is minimal and does not contribute to the length of the interview. The burden to the study participant is minimal with the entire interview taking only 1 to 1-1/2 hours.

The interview did not provide sufficient information to accurately assess positive and negative symptom profiles needed to complete the entire Brief Psychiatric Rating Scale (BPRS). In the pilot study, a majority of the questions on this instrument were scored as "not assessed" due to the fact that this study does not explore the individual's feelings and thoughts (e.g. suicidality, depression, anxiety, guilt, somatic concerns). This study is designed to be a one-time interview with individuals not previously known to the interviewer, thereby making it difficult to assess symptoms. Soliciting the primary therapists to complete the BPRS was too burdensome and, in many cases, the therapist would not be trained in completing this instrument. This measure was removed from the final study and was replaced by the Schizophrenia Rating Scale**,** described previously. This instrument is not redundant with the other measures and does not add to participant burden.

Table 7. Study measurements.

Measure	LQoL[5]	SOBI	NEO	DSM	CIQ	SNI	BPRS[4]	GAF	Records
Social Relationships	**X**			**X**	**X**	**X**			
Family Relationships	√					√			
Friendships	√					√			
Significant Others	√								
Member Relationships	√					√			
Distal Relationships				√					
Satisfaction w/ relations	√								
Diversity						√			
Embeddedness						√			
Network Size						√			
Frequency of Contact						√			
Type of Contact[1]						√			
Physical Health[2]	**X**								**X**
Legal Involvement	**X**								
Finances	**X**								
Life Satisfaction	**X**								
Daily Activities	**X**				**X**		**X**	**X**	
Level of Functioning[3]									
Personality			**X**						
Sense of Belonging		**X**							
Demographics/SES	**X**								**X**
Employment/Education	**X**				**X**	**X**			**X**
Housing Arrangement	**X**								**X**
Treatment History									**X**

1. Face to face, telephone, or written
2. LQoL physical health questions are subjective. The records form documented diagnosed medical problems
3. The information provided from the CIQ contributed information needed for the GAF rating
4. The BPRS was removed from the final study and replaced with the Schizophrenia Rating Scale.
5. The LQoLI interview collected demographic data as well as specific data about income source and amount.

4. Distal Support Measure Revisions

What follows is a detailed analysis of the changes made to the Distal Support Measure as a result of the pilot study.

1. The second interview yielded a greater number of responses to the question "Are there other places or circumstances where you are comfortable and have come to know people you haven't met at the clinic or through family?" resulting in participants having an increase in the total distal support scores in the second interview. Because distal support is not a source of support generally acknowledged, participants did not understand the concept at the outset of the interview. As the interview progressed, however, participants began to identify relationships of this nature. Therefore, a more explanatory script prior to the administration of the instrument to elicit accurate information on the sources and nature of distal support relationships was added. The script to be recited prior to beginning the interview was thus:

> *The following questions will be asking about your experience talking with other people you meet in the community who you have come to know and see frequently, like shop owners, wait staff, and employees who work in the places you go. These places could be your pharmacy, a coffee shop, neighborhood store, the library, community group or any place you go on a regular basis. I want you to focus only on your interactions and experiences with people you meet in the community, not people you meet at the clinic, the clubhouse/drop-in center or with family members. Each question is asking about your interactions over the past 3 months.*

2. In-depth probing was also needed when sources of distal support were identified. Again, because distal support is not a generally contemplated source of support, participants may

not have been fully cognizant of the nature of the relationship and the day-to-day interactions that support it.

The addition of the following standard questions for probing includes:

- How do you know they recognize you?
- Who recognizes you?
- Do they work there or are they there as a customer (member, etc.)? was asked when the participant answers "Yes" to the question "Do they recognize/acknowledge you when you come in?"
- Why do you look forward to spending time there? Is it because you know other people? Do you ever go there just to talk to the other people?
- What makes them a friend/acquaintance?"
- Examples will be given to the question "Do they sometimes help you out in times of need?" such as giving you coffee or food on the house, fronting goods until you have money again, talking to you when you feel anxious or nervous.

3. The question *Do you generally shop in the same grocery or drug store for the things you need?* (Question 1) resulted in two responses by two of the participants because they did not fill their prescriptions at the grocery store, thereby resulting in the use of the 'Other'. These two respondents had identified the staff at the pharmacy as sources of distal support. The pharmacy as a common source of distal support may be an important finding and therefore this question was divided into two separate questions:

"*Where do you shop to make the majority of your grocery purchases?*" and *"Where do you get your prescriptions filled?"*

4. Restaurants and local stores were the primary responses to the open-ended questions "*Do you have a favorite place where you hang out on a regular basis?*" Therefore questions that address specific types of establishments were added to the instrument with the questions "*Is there a restaurant or café you go to on a regular basis?"* and "*Is there a local store where you shop on a regular basis?"*.

5. The open-ended "Are there other places you hang out?" will remain and responses will be categorized into discrete variables for purposes of analysis. Coding for open-ended response of sources of distal support will be categorized as follows:

a. Restaurant/Café
b. Retail establishment
c. Library
d. Other

6. A predominant response to the question *Do they sometimes help you out in times of need?* was that help had never been requested or needed. This response should be distinct from the response of 'No', therefore the additional response category of "Never asked/Haven't needed help" was added to the question *Do they sometimes help you out in times of need?*

7. The pilot instrument did not include a time frame during which the distal relationship was active. Two respondents mentioned that they stopped frequenting an establishment shortly before the interview. To address this, participants were asked to include sources of distal support received at any time during the past 3 months, whether active at the time of interview or not. Three months was decided as a time frame that is not so distant it would be forgotten and not so narrow that it would eliminate sources of support influential to the participant's current functioning.

8. The pilot instrument included a question for respondents to recount their activities during the 7 days preceding the interview in an effort to capture sources of support not identified during the interview. This exercise, however, yielded little information. The majority of the respondents was unable to remember their activities and most guessed based on their usual routine. Furthermore, this portion of the instrument was time consuming and seemed to be frustrating to the respondents. Therefore this section was removed from the instrument.

9. The pilot instrument queried whether the participant knew the names of those with whom they interact at the identified establishment, but failed to query whether the reverse was true. It may be the case that a participant has not remembered or learned the names of the others encountered regularly, yet are known by name. This question will be a further measure of the familiarity of the participant to the people associated with the establishment and therefore the additional question *"Do they know your name?"* will be added to the instrument for Questions 1, 2, 3, 4, 5, 6 and 7a,b.

10. Although previous studies discussed the use of public transportation services as a place to gain a feeling of social connectedness, the goal of this study is to examine regular, everyday distal relationships with others. The difference between the two became evident during the pilot study and therefore the question "*Do you use public transportation?"* was eliminated in the final instrument.

11. It became apparent during the pilot study that a change in the ordering of the question would allow the interview to flow more easily and would serve to initiate the participant to the idea of distal support. The original interview began with the question *Do you have a favorite place where you hang out on a regular basis?* After administering the interview several

times, it became evident that when the interview was opened with this question, respondents were less likely to identify places that provide distal support. Beginning the interview with the questions addressing specific types of places (i.e. grocery store, drug store, place of worship) assisted the respondent to become more familiar with the idea of distal supports and thus more likely elicit responses that identify other places where support of this nature is received.

The questions in the final instrument were in the following order:

a. Grocery Store
b. Drug Store/Pharmacy
c. Place of worship
d. Restaurant/Café
e. Local store
f. Other favorite place(s)

12. The question "*Do you participate in church activities other than services?*" is not used in the scoring of the distal support measure and this information is collected in the Social Network Index, therefore it was removed from the final instrument.

13. The Distal Support Measure was designed to capture the presence of supportive casual community relationships, but, as stated earlier in this report, this is a source of support not generally contemplated – even to the individual in receipt of it. The addition of questions to the Distal Support Measure that elicit from the individual information about the supports s/he identifies as important to them results in a more rigorous examination of the support system, as well as to provide information that can be more fully explored in the body of this instrument. What follows is a breakdown of the questions added to the Distal Support Measure used as a lead to the measure, as well as the justification for each question. All questions pertained to the past 3 months.

Social Network:

a) Household composition: Of the instruments included in this study, none included a specific question about others with whom the respondent lives. This is important to discovering the day-to-day social contacts. This question was probed with the statement "Who else lives in your house/apartment?"

b) Extended family: This specifies family relationships the participant identifies outside the nuclear unit important to him/her. This question was probed with the statement "Do you have aunts, uncles, cousins or any other relatives with whom you feel close?".

c) Non-kin (neighbors, friends, classmates, clubs, lodges, hangouts, etc). This question is probed with the statements "Who else do you have out there?", "What about neighbors, friends?". Responses to these questions provide information that can be further explored when inquiring about distal supports.

d) Use of resources other than WPIC**:** Patient's sometimes seek help in dealing with their illness from a variety of resources that may include other social service agencies and health facilities, as well as clergy and alternative medicine practitioners. This assists in delineating other sources of support that may otherwise be undiscovered. Probes include "When you feel like you might be getting sick, who do you talk to about that?", "When the symptoms of your illness are uncomfortable to you, who helps to make it better for you?".

e) Core support system (person counted on, turned to, or confided in)**:**

This question is probed with the questions "Who do you talk to when you're feeling down?", "When you're out of money and need something, who helps you with that?", "When you want do something for fun, like go to a movie or shopping, who do you call?", "When you just feel like being with other people, where do you go?".

The addition of the questions outlined above allows for a focus on the participant's perception of available supports and provides information for further exploration into distal supports. These data were not used in the analysis, but served primarily as a lead in to enhance

the ability of the measure to collect information on distal supports. These additional questions added between 10 and 15 minute to the interview time.

5. Summary of the pilot study

Developing ease with the interview process and familiarity with the instruments was a significant element of the pilot study. This process led to a greater understanding of when and how to probe during the interview and assisted in identifying the questions most relevant to the goals of the Distal Support Measure and to identify questions that improve the validity of the instrument.

Retest scores yielded a greater number of total distal support sources, suggestive of a learning curve on the part of the respondents, the interviewer or, likely, both. The above outlined revisions to the Distal Support Measure were designed to improve the instrument's ability to identify all distal support sources in a single interview and to improve reliability significantly.

C. FULL STUDY RESULTS

1. Participation

Sixty-eight individuals were screened for participation, four were found to be ineligible due to failure meet age and diagnosis requirements by self-report. Sixty-four participants consented and were enrolled in the study. Six participants were found to be ineligible upon further review; three participants carried a primary diagnosis of Major Depressive Disorder, one participant had no record of treatment at UPMC-WPIC, and another participant had one

hospitalization at the beginning of the three-year period preceding the study, yet no record of outpatient treatment during the subsequent time period (records indicate that the participant spent the majority of that time incarcerated). Another participant was only in treatment for five months, not long enough to allow for extrapolation. Therefore these six participants were excluded from all analyses, leaving a total of 58 participants for the analysis. One participant, due to interviewer error, did not complete the NEO-FFI, therefore analysis involving these variables will have a sample size of 57.

Twenty-five of the participants learned of the study through the flyers posted at the clinic and were self-referred. The remaining 33 were referred from clinicians and psychiatrists treating patients at the CCS clinic.

Tables 8 and 9 show the descriptive statistics of the individuals participating in the full distal support study. Forty of the participants carried a diagnosis of schizophrenia (68.97%) and 18 carried a diagnosis of schizoaffective disorder (31.03%). The mean age of the 58 participants was 43.78 (SD=8.11, range 26 through 63 years). Nearly two-thirds were black (63.79%) and nearly half (48.28%) were male. The majority (89.66%) of participants were not married (65.52% never married, 24.14% separated/divorced). Few (6.90%) were living in housing supported through the mental health system. The majority (70.69%) of participants were unemployed and the mean monthly income was $869.59 (SD = 515.03, range $458.00 to $3,300.00). About half (48.28%) of the sample were educated beyond high school.

Table 8. Full study participant characteristics.

Sociodemographic Variable	Mean	Std. Dev.	Min.	Max.
Age	43.8	8.1	26	63
Years of education	12.8	2.7	8	20
Income (dollars per month)	869.59	515.03	458.00	3,300.00
	n		**%**	
Diagnosis				
Schizophrenia	40		69.0	
Schizoaffective disorder	18		31.0	
Gender				
Male	28		48.3	
Female	30		51.7	
Race				
White	21		36.2	
African-American	37		63.8	
Marital Status				
Married/Co-habitating	6		10.3	
Divorced/Separated	14		24.2	
Never married	38		65.5	
Current living arrangements				
Independent	54		93.1	
Supervised	4		6.9	
Employment Status				
Part-time	10		17.2	
Full-time	7		12.1	
Not employed	41		70.7	

* Includes alimony, family support, retirement benefits, savings, and inheritance.

2. Source of Distal Support

The first five sections of the distal support measure focus on particular establishments commonly frequented by the general population on an on-going basis. Included in these sections were the grocery store, the pharmacy, cafés/restaurants, and neighborhood stores. The fifth section focused on attendance of traditional religious institutions (e.g. church, synagogue, temple). The sixth section is open-ended with prompts designed to focus on attendance of community groups (e.g. AA/NA meetings). The seventh and eighth sections are open-ended in

order to provide the respondent the opportunity to identify places that were sources of distal support not specifically addressed in the preceding sections.

a. Grocery Store

The majority (82.76%, n = 48) of respondents did their own grocery shopping. Of those 48 (85.11%) shopped at the same grocery store for at least one year and nearly half of those who did their own shopping (41.38%) frequented the grocery store at least once per week. Most respondents (70.83%) looked forward to grocery shopping and felt welcomed by the employees (89.58%). More than half (64.58%) stated that they were recognized and acknowledged by the staff. Most, however, neither knew the names of any staff members (62.50%) nor was known by name (72.34%) and less than half (39.59%) characterized their relationship with staff as either a friendship (10.42%) or an acquaintanceship (29.17%). The majority (72.41%) said that they'd never needed or asked for help in any way. Five of the 7 respondents who reported that they had been helped reported that they had an occasion in which they were less than one dollar (20- 60 cents) short on cash to pay for the total bill, but were not denied the total purchase. One respondent was given a free turkey despite not having the appropriate coupon, and the third stated that one particular cashier would often let items "slip by" without being scanned and another frequently forgot his wallet and felt helped by the fact that his items were held until he returned with cash. Twenty-one of the 58 (36.21%) respondents in this study were calculated to have a distal support at the grocery store.

Table 9. Grocery store results.

Variable	N	%
Grocery shopping		
Yes, grocery shops	48	82.8
No, doesn't do the grocery shopping	10	17.2
Frequency of shopping (same grocery)		
Daily	1	02.1
More than once per week	13	27.1
Once per week	10	20.8
More than once per month	17	35.4
Monthly	7	14.6
Years shopping at specific grocery		
Less than one year	7	14.6
One to five years	19	39.6
Five or more years	22	45.8
Look forward to time there		
No	14	29.2
Yes	34	70.8
Recognized/acknowledged		
No	17	35.4
Yes	31	64.6
Feel welcomed		
No	5	10.42
Yes	43	89.6
Know the names of others there		
No	30	62.5
Yes	18	97.5
Other know their name		
No	34	72.3
Yes	13	27.7
Do they sometimes help		
No	2	04.2
Yes	7	14.6
Never asked	39	81.3
Perceived nature of the relationship		
No relationship	29	60.4
Friend	5	10.4
Acquaintance	14	29.2
Source of Distal Support		
Yes	21	36.21
No	37	63.79

b. Pharmacy

The majority (82.93%, n = 51) of respondents filled their prescriptions independently and most of those 51 (90.20%) used the same pharmacy for one or more years. All respondents frequented the pharmacy more than once per month. About one-third (64.71%) stated that they looked forward to their time there and the majority (94.12%) felt welcomed. Most (70.53%) were recognized and acknowledged by the people employed at the pharmacy and nearly half (45.10%) knew the name of at least one employee, while more (70.59%) were known by name. The majority (94.12%) said they never needed or asked for help. Of those who stated that they did receive help (19.64%, n= 10), the assistance was primarily (63.64%) in the form of maintaining the participant on their medications. This involved advancing medications after the prescription expired until the prescribing MD could be contacted or advancing medications on credit until payment could be made. One uninsured participant reported that he was given free samples. One participant stated that she enjoyed the conversations she had with the pharmacist and another stated that his pharmacist gave him $2.00 when they ran into each other outside of the pharmacy.

More than half (60.0%) perceived at least one relationship with an employee at the pharmacy to be that of an acquaintanceship, fewer (20.0%) perceived the relationship to be a friendship, and the remaining (20.0%) neither characterized the relationship as a friendship or an acquaintanceship. All reported that they were recognized and acknowledged at the pharmacy. More than half (62.86%) knew their pharmacists name and all but one (97.14%) was known by name. The majority (97.14%) had been using the same pharmacy for five or more years.

Of the total sample, 60.34% found their pharmacy to be a source of distal support.

Table 10. Pharmacy/drug store.

Variable	N	%
Pharmacy/drug store		
Yes, uses a pharmacy in person	51	89.9
No, doesn't get own medications	6	10.1
Frequency of shopping		
Daily	0	00.0
More than once per week	2	3.92
Once per week	6	11.8
More than once per month	13	25.5
Monthly	30	58.8
Years using the pharmacy		
Less than one year	5	9.8
One to five years	18	35.3
Five or more years	28	54.9
Look forward to time there		
No	18	35.3
Yes	33	64.7
Recognized/acknowledged		
No	15	29.4
Yes	36	70.6
Feel welcomed		
No	3	5.9
Yes	48	94.1
Know the names of others there		
No	28	54.9
Yes	23	45.1
Other know their name		
No	15	29.4
Yes	36	70.6
Do they sometimes help		
No	3	5.9
Yes	10	19.6
Never asked	38	74.5
Perceived nature of the relationship		
No relationship	21	41.2
Friend	7	13.7
Acquaintance	23	45.1
Source of Distal Support		
Yes	35	60.34
No	23	39.66

c. Café/restaurant/bar

Only about half (48.28%, n = 28) of the sample population identified a favorite café/restaurant that they frequented on a regular basis. Of those 28, the majority (85.71%) frequented the restaurant at least once per week and most (78.57%) had been doing so for at least one year. All but one stated that they looked forward to time spent there and the majority felt welcomed. The majority (82.14%) stated that they were recognized and acknowledged by at least one wait staff while there, but few (32.14%) knew the name of any staff or were known by name (39.29%). About half (53.57%) perceived their relationship with the wait staff as either a friendship (17.86%) or an acquaintanceship (35.71%). Nearly half (48.39%) of these respondents reported that they were acknowledged by being given some form of special treatment. The majority (80.0%) reported that they receive food or drinks on the house or at a discounted price at least some of the time. One participant stated that he had forgotten his money, but was trusted to pay the next time he came in; another stated that he had an arrangement in which he worked for food and also was frequently lent or given money by the staff; another stated that she was helped when a staff member exchanged a ten dollar bill for a roll of quarters.

Of the total sample population, 29.31% (n=17) fostered a distal support in a restaurant/café.

Table 11. Café/restaurant.

Variable	N	%
Café/Restaurant		
Yes, regular patron	28	48.3
No, not a regular patron	30	51.7
Frequency of patronage		
Daily	3	10.7
More than once per week	14	50.0
Once per week	7	25.0
More than once per month	0	00.0
Monthly	4	14.3
Years of patronage		
Less than one year	6	21.4
One to five years	14	50.0
Five or more years	8	28.6
Look forward to time there		
No	1	3.6
Yes	27	96.4
Recognized/acknowledged		
No	5	17.9
Yes	23	82.1
Know the names of others there		
No	19	67.9
Yes	9	32.1
Other know their name		
No	17	60.7
Yes	11	39.3
Do they sometimes help		
No	0	00.0
Yes	15	53.6
Never asked	13	46.4
Perceived nature of the relationship		
No relationship	13	46.4
Friend	5	17.9
Acquaintance	10	35.7
Source of Distal Support		
Yes	17	29.31
No	41	70.69

d. Neighborhood store

More than half (63.79%, n = 37) of the respondents reported that they patronized a neighborhood store on a regular basis and of those 37, 83.78% frequented the store at least once

per week and 83.78% have been doing so for one or more years. Most (81.08%) stated that they looked forward to shopping at the store and all but two (92.11%) stated that they were recognized and acknowledged by at least one employee. Nearly three-quarters (64.86%) knew the name of at least one employee and more than half (54.05%) were known by name. More than one-third (40.54%) stated that they received some form of help or favors from an employee; most (76.47%) reported receiving help in the form of credit for purchases, primarily cigarettes. One participant reported that an employee would sometimes reduce the price on certain items or would hold merchandise until the participant was able to pay; another participant reported that an employee would sometimes put in their own money if she was short of the total purchase price; others reported that they enjoyed hanging out and sharing conversations. Two-thirds (67.57%) of those who frequented a local store perceived their relationship with at least one cashier as being an acquaintance (35.14%) or a friend (32.43%).

Of the total sample population, 50% (n=29) fostered a distal support in at a neighborhood store.

Table 12. Neighborhood store.

Variable	N	%
Neighborhood store		
Yes, patronize a local store	37	63.8
No, do not patronize	21	36.2
Frequency of patronage		
Daily	7	18.9
More than once per week	19	51.4
Once per week	5	13.5
More than once per month	0	00.0
Monthly	6	16.2
Years patronized		
Less than one year	6	16.2
One to five years	18	48.7
Five or more years	13	35.2
Look forward to time there		
No	7	18.9
Yes	30	81.1
Recognized/acknowledged		
No	2	5.41
Yes	35	94.6
Know the names of others there		
No	13	35.1
Yes	24	64.9
Other know their name		
No	17	46.0
Yes	20	54.0
Do they sometimes help		
No	3	8.1
Yes	15	40.5
Never asked	19	51.4
Perceived nature of the relationship		
No relationship	12	32.4
Friend	12	32.4
Acquaintance	13	35.2
Source of Distal Support		
Yes	29	50.0
No	29	50.0

e. Place of Worship

Twenty (34.48%) of the participants reported attending religious services on a regular basis; 3 attended daily, 13 attended more than once per week, 2 attended once per week, and 2 attended more than once per month, but less than weekly. Most of these 20 participants (90%) had been attending the same place of worship for at least one year. All participants reported that they looked forward to time spent there and felt welcomed by other parishioners and the clergy. Most (80%) knew the names of at least one other parishioner and most were known by name (85%). Nearly half (45%) reported that they had received some form of assistance; provided in the form of clothing, food, money (70%), transportation to and from services (20%), and assistance during hospitalizations (e.g. communion while hospitalized, brought personal items to the hospital, assisted with expenses) (30%). One participant reported that her church helped with the funeral expenses for her grandchild, and others reported feeling helped by emotional support provided through conversations, hugs, invitation to holiday dinner, dining out). The majority (75.0%) reported at least one friendship (20.0%) or acquaintanceship (55.0%).

Of the total sample 29.31% of the participants fostered a distal support from a place of worship.

Table 13. Place of worship.

Variable	N	%
Place of worship		
Yes, attend a place of worship	20	34.5
No, do not attend	38	65.5
Frequency of attendance		
Daily	3	15.0
More than once per week	13	65.0
Once per week	2	10.0
More than once per month	2	10.0
Monthly	0	0.0
Years attending		
Less than one year	2	10.0
One – two years	5	25.0
Two to five years	5	25.0
Five or more years	8	40.0
Look forward to time there		
No	0	0.0
Yes	20	100.0
Feel welcomed		
No	0	0.0
Yes	20	100.0
Know other parishioners		
No	3	15.0
Yes	17	85.0
Know the names of others there		
No	4	20.0
Yes	16	80.0
Other know their name		
No	3	15.0
Yes	17	85.0
Do they help in times of need		
No	2	10.0
Yes	9	45.0
Never asked	9	45.0
Perceived nature of the relationship		
No relationship	5	25.0
Friend	11	55.0
Acquaintance	4	20.0
Source of Distal Support		
Yes	17	29.31
No	41	70.69

f. Favorite place to hang out

Twenty-six (44.83%) of the total sample identified at least one additional place where they spent their time. Of those 26, 84.62% of whom made contact at least once per week and 80.77% for one year or longer. Places identified included retail establishments (6.0%), restaurants/café (16.67%), community groups (primarily AA/NA) (40%), a public library (10%), community outreach centers (e.g. soup kitchens) (10%), a gym (6.67%), and other establishments (e.g. methadone clinic) (6.67%). The majority (92.31%) looked forward to the time spent there and most (92.31%) reported that they were recognized and acknowledge when there. Most (76.92%) knew the name of at least one person and were known by name (84.62%). More than two-thirds (69.23%) reported that they received some form of help, principally in the form of goods and credit on goods (e.g. food, loans of money) (20.00%), transportation (6.67%), and emotional support (i.e. encouragement, advice, conversation) (16.67%). More than three-quarters (89.66%) characterized their relationship with at least one other as a friendship (68.97%) or an acquaintanceship (20.69%).

Of the total sample 39.66% (n = 23) fostered a distal support in this category.

Table 14. Favorite place to hang out.

Variable	N	%
Favorite place to hang out		
Yes, has a favorite place	26	45.6
No, doesn't have a favorite place	31	54.4
Frequency of contact		
Daily	3	12.0
More than once per week	11	44.0
Once per week	9	36.0
More than once per month	0	0.0
Monthly	1	4.0
Occasionally only	1	4.0
Years of contact		
Less than one year	3	12.0
One to five years	19	76.0
Five or more years	3	12.0
Look forward to time there		
No	2	7.7
Yes	24	92.3
Recognized/acknowledged		
No	2	7.7
Yes	24	92.3
Know the names of others there		
No	6	23.1
Yes	20	76.9
Other know their name		
No	4	15.4
Yes	22	84.6
Do they sometimes help		
No	1	3.9
Yes	18	69.2
Never asked	7	26.9
Perceived nature of the relationship		
No relationship	3	11.5
Friend	17	65.4
Acquaintance	6	23.1
Source of Distal Support		
Yes	23	39.66
No	35	60.34

g. Other favorite place

Eighteen (31.03%) of the participants identified at least one more additional place in which they have frequent contact with others and five identified two additional places (8.62%). Of those 18 participants, places identified included restaurants/cafes (34.61%), retail establishments (34.81%), the public library (7.69%), community groups (7.69%), the post office (3.84%), a gym (3.84%), and bingo (3.84%). Nearly two-thirds (60.87%) of these participants had at least weekly contact and most (78.26%) had been frequenting the establishment for more than one year. The majority (86.96%) looked forward to the time they spent there and most felt welcomed (91.30%). More than two-thirds (69.57%) knew the name of at least one other person and about half (52.17%) were known by name. About three-quarters (69.57%) of these participants perceived their relationship with another there as either a friendship (34.78%) or an acquaintanceship (34.78%).

Of the total sample 31.03% (n= 18) fostered a distal support in this category.

Table 15. Other favorite place.

Variable	N	%
Other place 1		
Yes, has another place	23	39.7
No, doesn't have another place	35	61.3
Frequency at other place 1		
Daily	4	17.4
More than once per week	5	21.7
Once per week	5	21.7
More than once per month	3	13.0
Monthly	4	17.4
Occasionally only	2	8.7
Years going to other place 1		
Less than one year	5	21.7
One to five years	9	39.1
Five or more years	9	39.1
Look forward to time there		
No	3	13.0
Yes	20	87.0
Recognized/acknowledged		
No	2	8.7
Yes	21	91.3
Do you feel welcomed		
No	2	8.7
Yes	21	91.3
Know the names of others there		
No	7	30.4
Yes	16	69.6
Other know your name		
No	10	45.5
Yes	12	54.5
Do they help		
No	0	0.0
Yes	12	52.2
Never asked	11	47.8
Perceived nature of the relationship		
No relationship	7	30.4
Friend	8	34.8
Acquaintance	8	34.8
Source of Distal Support		
Yes	18	31.03
No	40	68.97

3. Distal Support Analysis

Score results of the Distal Support Measure are presented in Figure 2. Two (3.45%) of the participants had no distal supports, ten (17.25%) had only one distal support, 15 (25.86%) had two, fourteen (24.14%) had three, eight ((13.74%) had four, six (10.34%) had five, two (3.45%) had six, and one (1.72%) had seven distal supports.

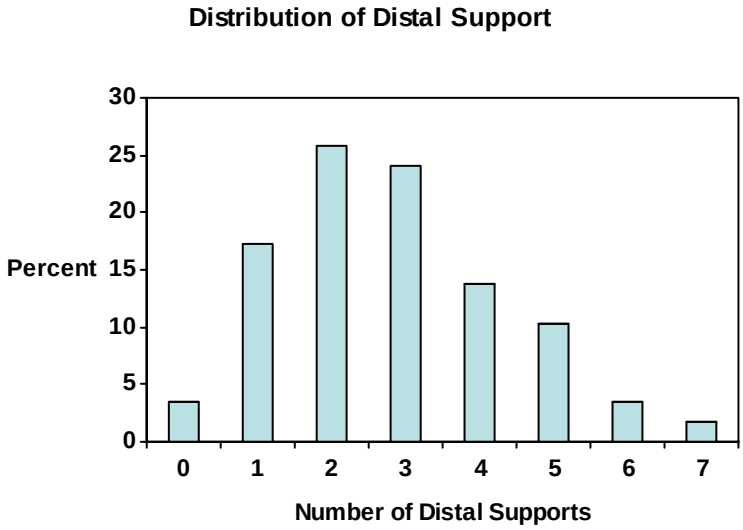

Figure 2. Distribution of distal supports.

a. Sociodemographic Characteristics

An examination of the associations of sociodemographic characteristics with the total number of distal supports revealed no statistically significant results. Figures 3, 4, and 5 show the distribution of distal supports according to the sociodemographic variables of age, years of education, and monthly income**.**

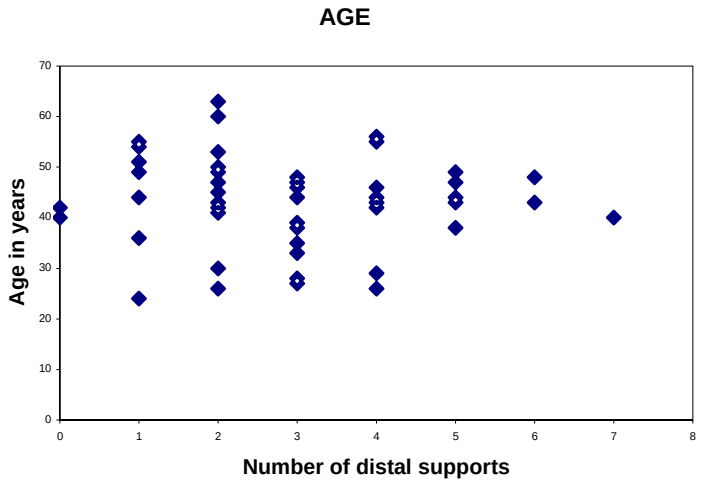

Figure 3. Distribution of age and total number of distal supports

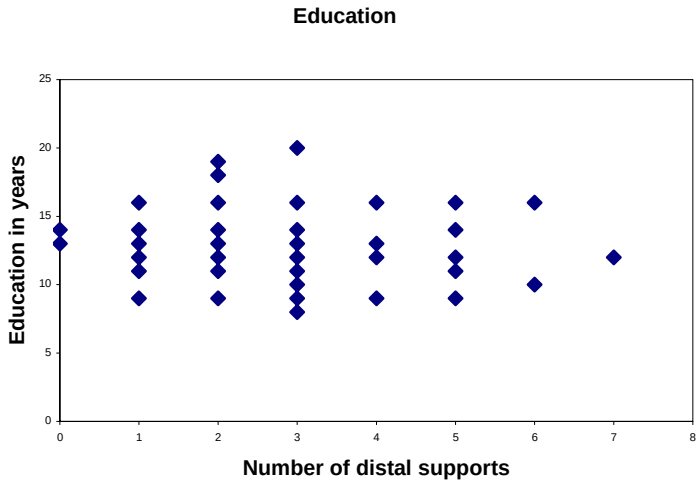

Figure 4. Distribution of education and total number of distal supports.

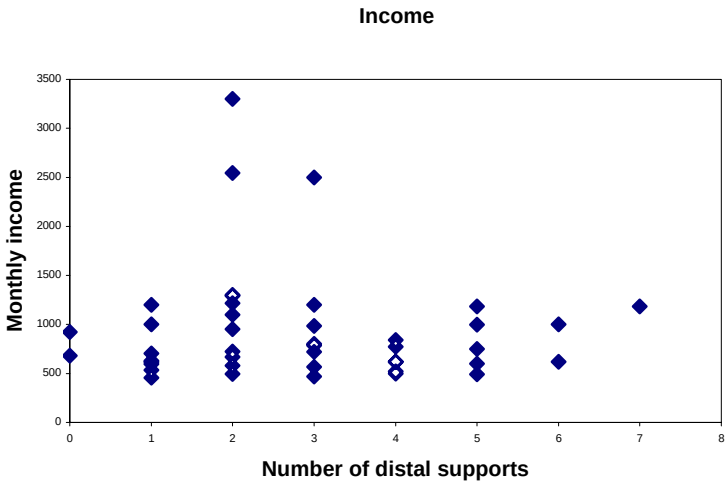

Figure 5. Distribution of Income and total number of distal supports

Table 16 shows the distribution of gender, race, marital status, and living situation among the participants. No significant associations were found between the number of distal supports and these sociodemographic characteristics.

Table 16. Distribution of number of distal supports by sociodemographic variables.

Sociodemographic	N	Mean	Median	Std. Dev.	Min.	Max.
Gender						
Male	28	2.5	2.0	1.5	0	5
Female	30	3.1	3.0	1.6	1	7
Race						
White	21	3.1	3.0	1.5	1	6
African-American	37	2.7	3.0	1.6	0	7
Marital Status						
Unmarried	52	2.8	3.0	1.6	0	7
Married	6	2.7	2.5	1.4	1	5
Housing situation						
Supervised	10	2.8	3.0	1.6	0	5
Independent	48	2.8	3.0	1.6	0	7

b. Hypothesis 1

The presence of distal supports will correlate positively with higher openness, extraversion, and agreeableness scores and lower neuroticism scores on the NEO-FFI, lower symptom profile scores on the SRS, and higher functional status scores on the CIQ and GAF.

Summary statistics for the personality, quality of life and sense of belonging measures can be found in Table 17. The mean global assessment of functioning score (47.6±10.06) indicated that the participants in this study suffered from serious impairments, the mean SRS score (3.02±2.72) indicates that the participants had low symptom profiles. The mean community integration scores (social integration 5.95±1.36, home integration 6.21±2.94, and productive integration 4.47±1.88) indicate that the majority of participants fell in the middle range of potential integration scores. Mean quality of life satisfaction scores suggest that

participants were relatively satisfied with their overall life (5.03±1.53) as well as with specific domains (housing 5.91±1.04, daily activities 5.08±1.39, family relationships 5.31±1.38, social relationships 5.13±1.42, sense of safety 5.44±1.31, and health status 5.36±1.14).

Table 17. Summary of personality, quality of life, and sense of belonging measures.

Measure	N	Mean	Std. Dev.	Min.	Max.
Openness	57	38.3	4.4	27	48
Extraversion	57	37.5	5.8	28	49
Agreeableness	57	38.4	4.6	29	48
Neuroticism	57	34.7	4.9	24	45
SRS score	58	3.0	2.7	0	10
GAF score	58	47.7	10.1	30	75
Social Integration	58	6.0	1.4	3	8
Home Integration	58	6.2	2.9	4	15
Productive Integration	58	4.5	1.9	1	7
Quality of Life					
General	58	5.0	1.5	1.5	7
Housing situation	58	5.9	1.0	3.0	7
Daily activities	58	5.1	1.4	1.7	7
Family relations	58	5.3	1.4	1.8	7
Social relations	58	5.1	1.4	1.2	7
Sense of safety	58	5.4	1.3	2.2	7
Health status	58	5.4	1.1	2.5	7
Sense of Belonging					
Sense of being valued	58	37.2	9.2	19	56
Desire for relations	58	32.1	4.5	20	43
Total SOBI	58	68.7	11.70	42	97

An examination of the correlations between the personality factors, quality of life and sense of belonging scores in the first hypothesis reveals that extraversion and openness to experience scores were strongly associated (Spearman r = .46, p-value .0003). These results suggest that participants who were more agreeable tended to be more neurotic, extraverted, and open to experience (Spearman r = .50, .31, .31 respectively, p-value = < .0001, .017, and .018, respectively) and that extroverted participants were more socially integrated (Spearman r = .31, p-value = .017). As would be expected, higher symptom profiles scores correlated strongly with lower functional status scores (Spearman r = -.68, p-value < .0001). Participants with higher

functional scores and lower symptom profile scores were more socially integrated (Spearman r = .43 and -.39, p-value = .001, .002, respectively).

Table 18. Association between personality and functional status

	Openness	Extravert	Agreeable	Neurotic	GAF	SRS
Openness (n=57)	1.0	0.5**	0.3*	0.2	-0.3*	0.1
Extraversion (n=57)		1.0	0.3*	0.29	0.1	-0.2
Agreeableness (n=57)			1.0	0.5**	-0.2	0.2
Neuroticism (n=57)				1.0	-0.2	0.3*
GAF					1.0	-.07**
SRS						1.0
Social integration	.1	0.3*	0.1	-0.1	.04**	-0.4**
Home integration	.2	0.2	0.1	0.2	-0.1	0.2
Productive integration	.1	0.1	0.1	-0.0	0.2	-0.2
Mean	38.3	36.9	38.4	34.7	47.7	3.0
SD	4.4	7.1	4.6	4.9	10.1	2.7

* p = < .05. ** p = < .001

Table 18. Continued.

	Soc. Int.	Home Int.	Prod. Int.
Social integration	1.0	-0.1	0.3*
Home integration		1.0	-0.1
Mean	6.0	6.2	4.5
SD	1.4	2.9	1.9

* p = < .05. ** p = < .001

As hypothesized, there was a strong positive correlation between both open and extraverted personality scores and the total number of distal supports (Spearman r = .37 and .42, p-value = .004 and .008, respectively). A positive, non-significant association was found with agreeableness (Spearman r = .17, p-value = .223); no association was found with neuroticism (Spearman r = .02, p-value = .830). A positive association between the number of distal supports and higher functional status (Spearman r = .21, p-value = .110) and a negative association was

found with symptom profile (Spearman r = -.17, p-value = .192), but these relationships were not statistically significant.

Table 19. Association of personality factors and functional status with the total number of distal supports

Dependent Variable	r
Openness	0.4**
Extraversion	0.4**
Agreeableness	0.2
Neuroticism	0.0
GAF score	0.2
SRS score	-0.2
Social Integration	0.2
Home Integration	-0.0
Productive Integration	0.2

* p = < .05, ** p = < .01

To further examine these associations, stepwise linear regression including all the predictor variables (sociodemographic characteristics, personality factors, overall quality of life score, functional status and symptom profile scores, and sense of belonging score) was employed using the forward stepwise selection to identify factors independently associated with distal supports. Results revealed that female gender (β = .87, p-value = .014), an open personality (β = .19, p-value = <.0001), and higher global functioning (β = .05, p-value = .007) were significantly associated with the number of distal supports.

Table 20. Factors independently associated with distal support.

Dependent Variable	β	SE	Partial R^2	ρ
Gender (reference = male)	0.9	0.34	0.09	.014
Openness to experience	0.2	0.04	0.04	<.0001
Higher global functioning	0.1	0.02	0.06	.007

c. Hypothesis II

The presence of distal supports will correlate positively with greater life satisfactions scores on the LQoLI and lower sense of belonging scores on the SOBI.

An examination of the associations between the dependent variables reveals that all quality of life satisfaction scores were highly correlated. In terms of sense of belonging, strong positive correlations were found between the sense of being valued and the total sense of belonging scores and all quality of life measures. Correlations were less strong between the desire for relationships and quality of life scores, with only housing, daily activities, and social relationships satisfaction scores reaching significance. Table 15 provides a detailed examination of these findings.

Table 21. Association of Quality of Life and Sense of Belonging scores.

	General	Housing Situation	Daily Activity	Family Relations	Social Relations	Sense Safety	Health Status
Quality of Life							
General	1.0	0.6**	0.8**	0.6**	0.8**	0.4*	0.7**
Housing situation		1.0	0.6**	0.6**	0.5**	0.5**	0.5**
Daily activities			1.0	0.7**	0.7**	0.6**	0.7**
Family relations				1.0	0.5**	0.5**	0.5**
Social relations					1.0	0.5**	0.5**
Sense of safety						1.0	0.5**
Health status							1.0
Sense of Belonging							
Sense of value§	-0.7**	-0.4*	-0.6**	-0.5**	-0.7**	-0.3*	-0*
Desire for relations	-0.1	-0.3*	-0.3*	-0.2	-0.3*	-0.3	-0.2
Total SOBI score	-0.6**	-0.4*	-0.6**	-0.5**	-0.7**	-0.4*	-0.4*
Mean	5.03	5.91	5.08	5.31	5.13	5.44	5.36
SD	1.53	1.04	1.39	1.38	1.42	1.31	1.14

* $p < .05$, ** $p < .001$

§ Lower SOBI scores indicate higher sense of belonging.

An examination of the relationship between total number of distal supports and quality of life and sense of belonging scores reveal significant positive associations between the number of distal supports and higher ratings on overall life satisfaction (Spearman r = .35, p-value = .008), satisfaction with social relationships (Spearman r = .34, p-value = .015), and satisfaction with daily activities (r = -.32, p-value = .015). In terms of the sense of belonging scores, participants who had a stronger desire for relationships (r = -.30, p-value = .027) and a greater overall sense of belonging (r = -.29, p-value = .027) tended to have more distal supports.

Table 22. Association of QoL, Sense of Belonging scores and distal supports.

Measure	Total Distal Supports r
Quality of Life measures	
General	0.4*
Living situation	0.2
Daily activities	0.3*
Family relations	0.1
Social relationships	0.4**
Feelings of safety	0.2
Health status	0.2
Sense of Belonging†	
Sense of being valued	-0.2
Desire for relationships	-0.3*
Total Sense of belonging	-0.3*

* p = < .05., ** p = < .001
† Lower scores indicate higher sense of belonging.

Stepwise linear regression analysis including all possible confounding variables analysis was employed using the forward stepwise selection to examine the independent association of the (ranked) overall quality of life satisfaction score with total number of distal supports. Included as possible confounding variables were the sense of belonging score, personality factors, functional and symptom profile scores, and sociodemographic variables.

Table 23 summarizes these results. Living in independent housing (β = 11.6, p-value = .009), an open personality (β = 1.7, p-value = .006), being African-American (β = 8.9, p-value = .012), and a higher sense of belonging (β = -0.9, p-value = <.0001) were found to be associated with overall life satisfaction. The total number of distal supports was not found to be significantly associated with life satisfaction scores, but results suggest that for each unit increase in the number of distal supports, the quality of life rating increases by 0.7.

Table 23. Independent association of factors associated with Quality of Life satisfaction.

Overall Life Satisfaction	β	SE	Partial R^2	p
Housing status (reference = supervised)	11.6	4.31	0.05	.009
Openness	1.2	0.41	0.06	.006
Race (reference = Caucasian)	8.9	3.43	0.06	.012
Sense of Belonging†	-0.9	0.15	0.30	<.0001
Number of distal supports*	0.7	1.15	<0.1	.560

* Forced into the model
† Lower scores indicate higher sense of belonging.

As summarized in Table 24, a higher overall sense of belonging was associated with living in supervised housing (β = 7.0, ρ = .025), being Caucasian (β = 6.5, ρ = .008), a higher overall life satisfaction (β = -4.9, ρ = <.0001), and a less open personality (β = 0.6, ρ = .047). The total number of distal supports was not found to be significantly associated with the sense of belonging, but there was a trend suggesting that for every unit increase in the number of distal supports, a lower (improved) score of 1.3 would be expected in the sense of belonging score.

Table 24. Independent association of factors associated with a sense of belonging.

Sense of Belonging †	β	SE	Partial R^2	ρ
Housing status (reference = supervised)	7.0	3.05	0.04	.025
Race (reference = Caucasian)	6.5	2.38	0.04	.008
Overall life satisfaction	-4.9	0.81	0.30	<.0001
Openness to experience	0.6	0.29	0.03	.047
Number of distal supports*	-1.3	0.79	<0.1	.112

* Forced into the model
† Lower scores indicate higher sense of belonging.

d. Hypothesis III

Measures of distal support will correlate negatively with the number of contacts with mental health services, even when scores on symptom profile and functional status are controlled statistically.

Table 25 provides descriptive statistics of the number of contacts with WPIC services broken down by CCS services (outpatient and partial hospitalization), case management services (Intensive case management/Resource Coordination/Continuous Treatment Team), hospitalizations, and emergency room visits.

Table 25. Distribution of mental health services contacts

Contacts with mental health services	Mean	Median	SD	Min.	Max.
Number of contacts w/ CCS services*	190.5	103.5	207.5	15	927
Number of contacts w/ CM (n=30)	152.1	111.0	210.7	1	1163
Total number of contacts §	269.2	193.5	262.6	19	1178
Number of hospitalizations	1.1	0	2.1	0	12
Number of emergency room visits	1.8	0	3.5	0	17

* All contact data measures contacts over the past 3 years
§ Total of CCS contacts and Case management contacts

Figures 6, 7 and 8 present the distributions of frequency contact with ambulatory services broken down by CCS contacts, case management contacts, and the total of all ambulatory contacts.

Figure 6 shows the distribution of frequency of contact with the combined total of outpatient and partial hospitalization services by number of distal supports and reveals a wide variation in the number of ambulatory contacts, with a range from 15 to 927.

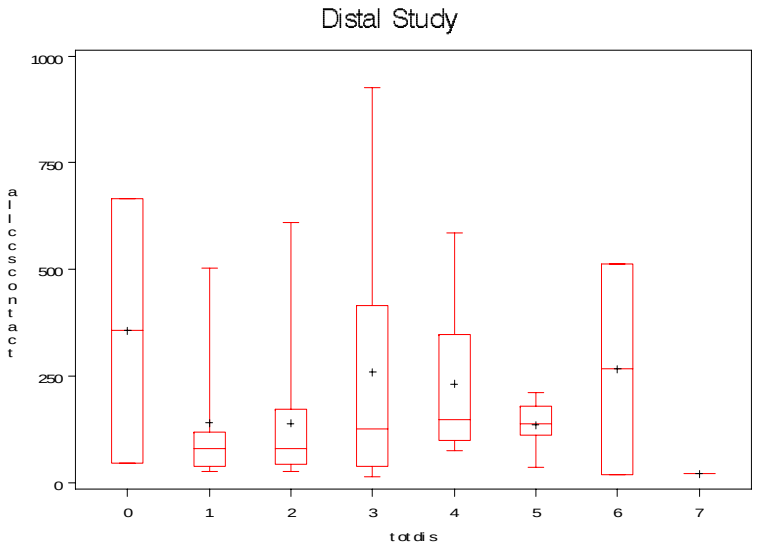

Figure 6. Distribution of CCS contacts by number of distal supports.

Figure 7 shows the distribution of frequency of contact with case management services by number of distal supports. Likewise, a wide variation in the number of case management contacts is revealed with a range from 1 to 1,163.

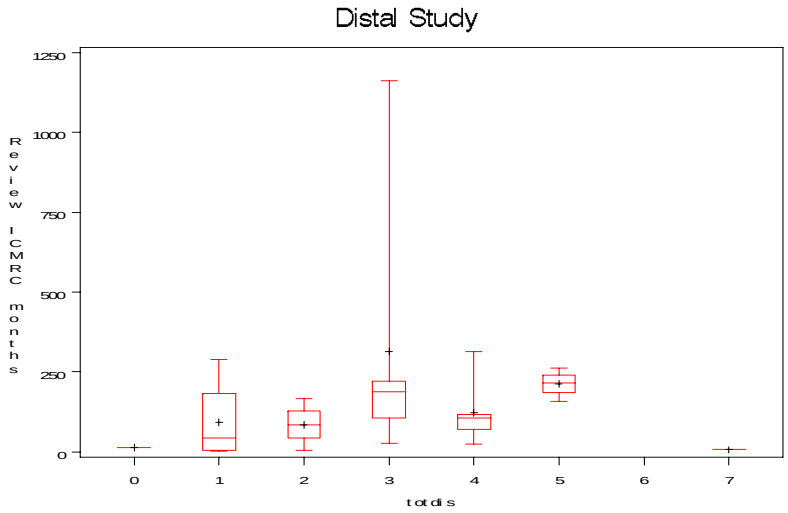

Figure 7. Distribution of case management contacts by number of distal supports.

Figure 8 shows the distribution of contact with the combined total of outpatient, partial hospitalization, and case management services in the three years preceding the study. Again, a wide variation in the number of all ambulatory contact is found, with a range is from 19 to 1,178.

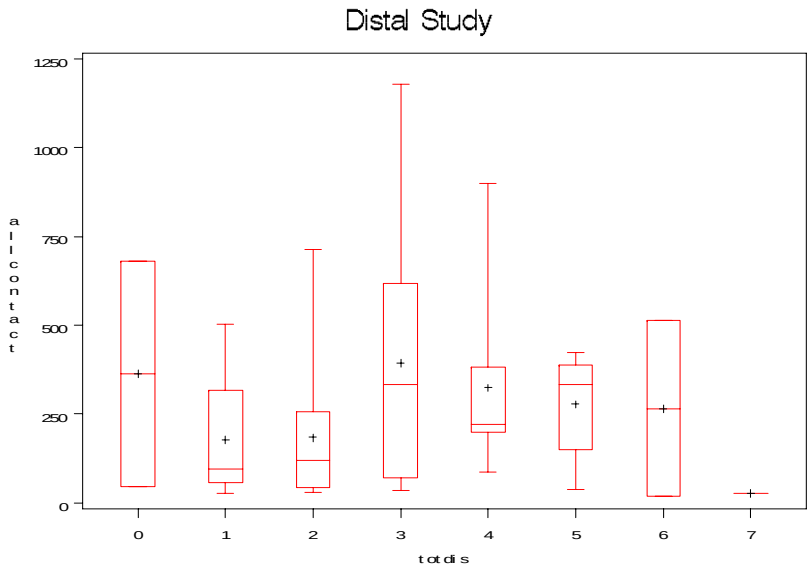

Figure 8. Distribution ambulatory contacts by number of distal supports.

Figures 9 and 10 present the distributions of hospitalizations and emergency contacts.

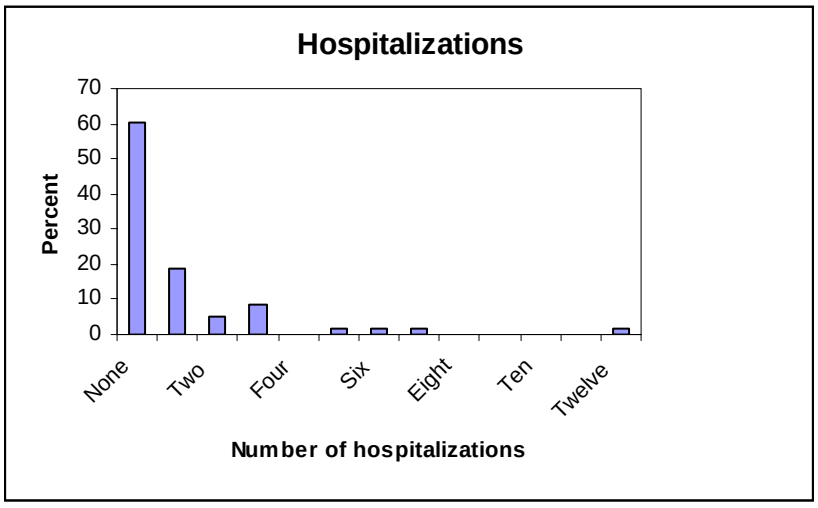

Figure 9. Distribution of number of hospitalizations

As presented in Figure 9, the distribution of hospitalizations has a wide variation. More than half of the participants (60.3%, n = 35) experienced no hospitalizations during the three

years prior to the study, and about a quarter (24.1%, n = 14) of the participants experienced one or two hospitalizations and the remaining nine (15.5%) experienced three or more hospitalizations, with one participant averaging four hospitalizations per year.

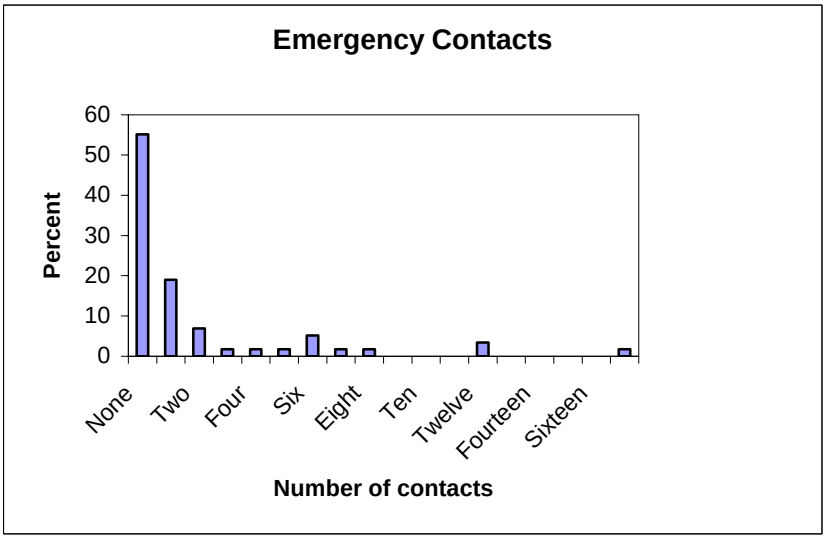

Figure 10. Distribution of Emergency Contacts

As presented in Figure 10, there is also a wide distribution of emergency contacts. More than half the participants had no emergency contacts during the three years prior to the study (55.17%, n = 32), and about a quarter (25.86%, n = 15) had one or two contacts, the remaining eleven participants (18.79%, n = 11) had three or more contacts, one of whom had seventeen emergency contacts during this time period. The fact that most in-patient hospitalizations are arranged through emergency services explains why the distribution of hospitalizations and emergency contacts are similar.

Contrary to the *a priori* hypothesis, the number of contacts with mental health services was not inversely related to the number of distal supports. In fact, increased hospitalization rates

were significantly associated with higher numbers of distal supports (Spearman r = .28, p = .032). A positive, non-significant association was found between the number of emergency contacts (Spearman r = .24, p-value = .065) and contacts with case management services (Spearman r = .34, p-value = .066, n = 30) and the number of distal supports.

Table 26. Association of ambulatory contacts with number of distal supports

Service type	r
CCS (outpatient and partial hospitalization)	0.1
ICM/RC/CTT (n=30)	0.3
All outpatient contacts	0.1

* p = < .05

Hospital and emergency service contacts were grouped into the following categories based on the literature (Corin and Lauzon, 1992): individuals who had no hospitalizations or emergency contacts during the three-year period, those with one-two hospitalizations or emergency contacts, and those with three or more hospitalizations or emergency contacts. Table 27 shows the breakdown of the categorized hospital and emergency room variables.

Table 27. Distributions of categorized in-patient and emergency contacts.

	N	%
Number of Hospitalizations		
No hospitalizations	35	60.3
One – two hospitalizations	14	24.1
Three or more hospitalizations	9	15.5
Emergency room visits		
No emergency services	32	55.2
One to two emergency services	15	25.9
Three or more emergency services	11	18.9

Participants who were not hospitalized in the preceding three years had a lower mean number of distal supports (2.46±1.34) than participants who had one to two hospitalizations

(3.36±1.95) as well as those who had three or more hospitalizations (3.33±1.41) (ANOVA F(2, 57) = 2.41, p = .099). This finding was also true with the number of emergency contacts: participants who had no emergency contacts in the preceding three years had a lower mean number of distal supports (2.50±1.37) than either the participants who had one to two contacts (3.13± 1.85) or three or more contacts (3.27±1.56) (ANOVA F(2, 57) = 148, p = .236).

Table 28. Distribution of total distal supports by hospitalization and emergency contacts.

	n	Mean	Std. Dev.	Min.	Max.
Hospitalizations					
None	35	2.5	1.3	0	6
One – two	14	3.3	2.0	0	7
Three or more	9	3.3	1.4	1	6
Emergency services					
None	32	2.5	1.4	0	6
One – two	15	3.1	1.9	0	7
Three or more	11	3.3	1.6	1	6

To examine the independent effects of distal support on the number of contacts with mental health services, univariate regression analysis was performed to look at the association of distal support with ambulatory contacts, no significant associations were found. Table 29 summarizes these results

Table 29. Independent association of distal support related to ambulatory contacts.

	Distal Support - Unadjusted			
	β	SE	Partial R^2	p
CCS contacts	0.02	0.09	0.00	.815
Case management contacts	0.25	0.17	0.07	.165
All ambulatory contacts	0.06	0.10	0.01	.540

To examine the independent effect of distal support on the number of contacts with outpatient mental health services, stepwise linear regression analysis was employed. Included as possible confounding variables were the sense of belonging scores, personality factors, functional and symptom profile scores, and sociodemographic variables. Results can be found in Table 30.

In terms of CCS contacts alone (the sum of partial hospitalization and outpatient contacts during the prior three years for each participant), no independent factors reached a level of significance.

In terms of case management contacts (the sum of all contact with ICM, RC, or CTT during the prior three years), independent associations were found with lower community integration ($\beta = -0.1$, p-value = .056), a more neurotic personality ($\beta = 0.1$, p-value = .013), a higher overall life satisfaction ($\beta = -0.4$, p-value = .028), and being African-American ($\beta = 1.5$, p-value = .009). The number of distal supports was found to have a positive associations with the number of case management contacts, but the relationship was not significant ($\beta = 0.1$, p-value = .449).

In terms of all ambulatory contacts (sum of CCS and case management service contacts), an independent association was found only with a lower community integration score ($\beta = -0.1$, p-value = .056).

Table 30. Independent association of factors related to ambulatory contacts.

	Distal Support Adjusted			
Dependent Variable	**β**	**SE**	**Partial R^2**	**ρ**
CCS contacts				
Number of distal supports*	0.0	0.09	---	.898
Case management services (n=30)				
Race	1.5	0.54	0.19	.009
Community Integration	-0.1	0.06	0.07	.056
Neuroticism	0.1	0.05	0.08	.013
Overall life satisfaction	0.4	0.19	0.09	.028
Number of distal supports*	0.1	0.15		.449
All ambulatory contacts				
Community Integration	-0.1	0.04	0.04	.052
Number of distal supports*	0.0	0.10	---	.863

* Forced into the model

To further examine the relationship of factors associated with the frequency of hospitalizations and emergency contacts, separate stepwise multinomial regression analysis was employed. Included as possible confounding variables were the sense of belonging scores, personality factors, functional and symptom profile scores, and sociodemographic variables.

Results revealed that a less neurotic participants were at a 70% reduced odds of being hospitalized (O.R. = 0.7, χ^2 = 12.3) and participants who had a more open and agreeable personality increased their odds of hospitalization by 30 and 40%, respectively (O.R. = 1.3 and 1.4, χ^2 = 12.3 and 5.1, respectively). An overall lower life satisfaction rating increased the odds of hospitalization by 30% (O.R. = .04, χ^2 = 1.3). The number of distal supports was not found to have a statistically significant effect on the number of hospitalization after other variables were factored in. These results do not support the hypothesis that having distal supports is associated with fewer hospitalizations, but instead participants with more distal supports were 1.4 times more likely to be hospitalized.

Table 31. Independent association of factors related to hospitalizations.

Predictors	β	O.R.	95% Confidence Interval	Wald χ^2	ρ
Race	2.4	10.7	1.87, 61.58	7.1	.008
Agreeableness	0.2	1.3	1.03, 1.57	5.1	.024
Openness to experience	0.4	1.4	1.18, 1.77	12.3	.000
Neuroticism	-0.3	0.7	0.60, 0.87	12.1	.000
Overall life satisfaction	-0.8	0.4	0.25, 0.78	8.0	.005
Total number of distal supports	0.3	1.4	0.89, 2.23	2.2	.142

* Forced into the model

Results revealed that the total number of distal supports (O.R. = 1.6, $\chi^2 = 5.8$), being African-American (O.R. = 7.9, $\chi^2 = 8.6$), and a higher symptom profile (O.R. = 0.3, $\chi^2 = 6.2$) were associated with more emergency contacts. These results do not support the hypothesis that having distal supports is associated with lower rates of emergency services use, but instead participants with more distal supports were 1.6 times more likely to use emergency services.

Table 32. Independent association of factors related to emergency contacts.

Predictors	β	O.R.	95% Confidence Interval	Wald χ^2	ρ
Number of distal supports	0.5	1.6	1.09, 2.31	5.8	.016
Race (reference = Caucasian)	2.1	7.9	1.99, 31.65	8.6	.003
SRS	0.3	1.3	1.06, 1.69	6.2	.013

VII. SUMMARY AND CONCLUSIONS

This study was designed to examine the characteristics and outcomes associated with the fostering of distal supports in the community in a sample population of individuals diagnosed with schizophrenia and schizoaffective disorder.

Research has demonstrated that the placement of the seriously and persistently mentally ill individuals in the community often fails to result in successful integration with the attendant privileges and benefits of community life - participation in community activities, social opportunities with other community members, and a sense of being a part of the larger society. Often, it has been argued, the seriously mentally ill individual merely become re-institutionalized in less restrictive, but fundamentally segregated circumstances.

The majority of studies examining the social integration of individuals diagnosed with psychotic disorders have focused on the normative, traditional measures of success aspired to by all members of society – steady employment, the support of friends, family, and co-workers, as well as recreation involving cultural activities. Little is known about how individuals with psychotic disorders function with other members of the community with whom they have routine encounters; the normative interactions required when patronizing retail and service establishments, and as members of community groups – situations in which the protective custody of the mental health system or peer support is absent. Most importantly, an examination of the importance of these interactions to integration, and by extension, recovery, has only

recently received attention (Corin,1998, Corin & Lauzen, 1992, Beal, 1999). This study sought to further explore this topic using quantitative methods.

A quantitative measure of distal supports was designed and tested in this study. This study succeeded in demonstrating that the participants fostered relationships with members of the community promoted by regular encounters in public places. All but two (96.56%) of the participants in this study identified at least one source of distal support in the community. Places like the grocery store (36.21%), the pharmacy (65.51%), restaurants (44.83%), neighborhood stores (53.45%), places of worship (29.31%), and other establishments including community groups, gyms, and libraries (32.76%) were identified as sources of distal support. An exploration of the factors associated with having distal supports and the possible benefits follows.

A. GENERAL FINDINGS – DISTAL SUPPORT MEASURE

This is the first instrument to quantitatively measure the presence of distal supports and therefore a comparison with other instruments cannot be made. The face validity of the Distal Support Measure, however, is supported by a strong correlated with other variables in the hypothesized direction. A greater number of distal supports were found to be associated with more open (Spearman r = 0.4, p-value = .005) and extraverted (Spearman r = 0.4, p-value = .001) personality factors, higher overall quality of life satisfaction ratings (Spearman r = 0.4, p-value = .008), and a greater sense of belonging (Spearman r = -0.3, p-value = .030).

The questions included in this instrument were based on the findings of previous qualitative studies (Corin & Lauzon, 1992, Beal, 1999) in which participants reported valuing their routine interactions with others - many of whom were identified as friends - at restaurants,

retail establishments and other public places. The data from the Distal Support Measure had findings consistent with these studies, suggesting good content validity. Participants identified places they enjoyed frequenting on a routine basis where they reported having friendships or acquaintanceships. The majority of the participants were found to have at least one distal support in the community based on information reported about their familiarity (i.e. being recognized, exchange of names) with other community members with whom they interact on a regularly and their perception of the relationship (i.e. friend or acquaintance).

B. GENERAL FINDINGS – PERSONALITY FACTORS AND FUNCTIONAL STATUS.

It was hypothesized that there would be positive correlations between the number of distal supports and openness, extraversion and agreeableness personality factors, and a negative correlation with neuroticism. This hypothesis is supported in part by the data. The personality factors of openness to experience (Spearman r = .37, p = .005) and extraversion (Spearman r = .42, p = .001) were found to be significantly associated with the number of distal supports. This makes intuitive sense because individuals who are extroverted tend to be sociable, outgoing, and talkative and individuals who are open to experience tend to be curious, independent, and have a desire to explore the world around them. Individuals with these personality characteristics would therefore be more likely spend time in the community and to interact with others while there.

The statistical evidence did not support an association with the personality trait of agreeableness (Spearman r = .22, p = .105) and a higher number of distal supports, although results suggest a positive relationship. No association was found between neuroticism and a higher number of distal supports (Spearman r = .03, p = .830). Individuals with agreeable

personality traits tend to be more compassionate, cooperative and helpful; traits that are central to forming and sustaining meaningful relationships, but less significant to the process of developing casual relationships. Therefore it would follow that this personality factor would play a less influential role in fostering distal supports. Likewise, results revealed no association between lower neuroticism scores and a greater number of distal supports ($\beta = 0.03$, p-value = .830).

Personality characteristics have been increasingly understood to be enduring and stable traits throughout each individual's lifetime. Recent research has demonstrated that the effect of schizophrenia does not alter the stability of the individual's personality traits and that the basic premorbid personality remains stable throughout the course of the schizophrenic illness (Lysaker, 1999). In a study of the effects of personality factors on the course and outcome of schizophrenia (Lysaker, et.al, 1999), it was found that participants with higher extraversion scores had lower scores on levels of emotional discomfort, as well as decreased positive and negative symptoms scores. These researchers reasoned that extroverted individuals have a greater tendency to seek out and rely upon social support. Social support, in turn, acts as a buffer against stress, resulting in lower levels of emotional distress. Reduced emotional distress results in a decreased risk for relapse (i.e. increased symptoms of hallucinations and delusions). Conversely, these researchers also found that higher neuroticism scores were suggestive of higher emotional discomfort scores, as well as higher positive symptom scores. Individuals with high levels of neuroticism were found to more likely suffer from feelings of emotional discomfort, self-consciousness, and vulnerability and tend to have a more passive and avoidant coping style.

The results of this study support these findings. Higher extraversion scores were significantly associated with higher social integration scores (Spearman r = .37, p = .005), a higher rating of satisfaction with social relationships (Spearman r = .39, p-value = .003), and lower symptom profile scores (Spearman r = -27, p = .036). A significant association was found between higher neuroticism scores and higher symptom profile scores (Spearman r = .27. p = .046) and a lower degree of satisfaction with social relationships (Spearman -.27, p-value = .044) and lower social integration scores (Spearman -.05, ns), but this association was weak. Most significantly, participants with high extraversion scores were found to have a greater number of distal supports (Spearman r = .42, p = .001).

Functional status, symptom severity, and community functioning were not found to have significant associations with the number of distal supports. It must be noted that the reliability of the GAF and SRS scores is compromised by the fact that the ratings on these scales were based upon observations made and information collected during a short interview, and were not based upon a full clinical examination. However, the GAF was highly correlated with the SRS (Spearman r = -0.7, p-value <.0001), suggesting that these measures offer a degree of reliability.

Results of multivariable linear regression analysis revealed that openness to experience was found to be the most significant personality factor (β = .19, p-value = < .0001) associated with the number of distal supports. Other factors independently associated with a greater number of distal supports were female gender (β = 0.8, p-value = .014) and a higher functional status (β = 0.1, p-value = .007). Research has demonstrated that females are more likely to seek support than are men and therefore may explain this finding. Participants who are higher functioning would be expected to spend more time in the community.

Overall, the results of this study confirm that personality characteristics, particularly openness to experience, are associated with fostering distal supports in the community.

C. GENERAL FINDINGS - QUALITY OF LIFE AND SENSE OF BELONGING

Studies have found that supportive social relationships are positively associated with both objective and subjective quality of life ratings among persons with severe mental illness (Yanos, et. al., 2001). Although these studies have examined association with relationships involving a greater depth of emotion and more meaningful interactions (i.e. family, friends, co-workers) than is involved in casual relationships, it is useful to examine the contributions of distal support to an improved quality of life.

The second hypothesis predicted that there would be a positive correlation between the total number of distal supports and subjective quality of life ratings. The data support this hypothesis in the domains one might expect to be effected by the routine interactions provided through distal supports; specifically overall life satisfaction (Spearman $r = .35$, $p = .008$), satisfaction with daily activities (Spearman $r = .32$, $p = .015$), and social relationships (Spearman $r = .34$, $p = .008$). The evidence is less supportive in terms of satisfaction ratings in the domains of housing status (independent vs. supervised), family relationships, and health status (Spearman $r = .17$, $.14$, and $.20$, p-values $.201$, $.313$, and $.142$ respectively), domains one would not necessarily expect to be influenced by the presence of distal supports. A trend toward significance was found with higher ratings of satisfaction in the domain of personal safety and the total number of distal support (Spearman $r = .24$, p-value $= .074$). It may be that the presence of distal supports in the community provided participants with a greater sense of protection and safety.

It was also hypothesized that a greater number of distal supports in the community would be associated with a higher sense of belonging. This was supported by the data; a greater number of distal supports was associated with a higher total sense of belonging score (Spearman r = -.29, p-value = .027), a greater desire for relationships (Spearman r = -.30, p-value = .027), and a trend toward significance with a sense of being valued (Spearman r = -24, p-value = .077). This finding may be explained by the fact that distal relationships generally do not involve a reciprocal exchange and therefore would not be as likely to contribute to the individual's sense of being valued.

The number of distal supports, however, was not found to be significantly associated with either an improved quality of life satisfaction or a greater sense of belonging after controlling for potentially confounding variables. However, the results suggest that for each unit increase in distal support, it is predicted that there would be a 0.7 unit decrease in the overall life satisfaction rating and for each unit increase in distal support, and that there would be a 1.3 unit increase in sense of belonging. The sample size may be too small to adequately adjust for confounding. The results may be compromised by the fact that the number of distal supports is confounded with personality factors, as well as other outcome measures found to be associated with the number of distal supports.

D. GENERAL FINDINGS – MENTAL HEALTH CONTACTS

The third hypothesis predicted that a greater number of distal supports would result in a decreased reliance of mental health services. This was not supported by the results; in fact the contrary was true. Non-significant positive associations were found between number of distal supports and contacts with outpatient services (both outpatient and partial hospitalization) and

the total of all ambulatory services (i.e. outpatient, partial hospitalization, and case management) suggesting that participants who had a greater number of distal supports had more ambulatory contacts When examined separately, the number of distal supports was found to have a significant positive association with case management services (Spearman r = 34, p-value = .066, n = 30). Results of multinomial regression analysis suggest that a greater number of distal supports is associated with a higher number of emergency contacts (O.R. = 1.6, p-value = .016) as well as a positive, non-significant association with the number of hospitalizations (O.R. = 1.4, p-value = .142). This is contrary to the findings of the study conducted by Corin & Lauzon (1992), in which a reduction in hospitalization rates was found among participants who fostered community supports. In that study the reasons attributed for this included a stance of "positive withdrawal" whereby the individual does not aspire to the more normative goals of society and thus feels more comfortable in his/her position. This, the researchers theorized, resulted in fewer relapses and subsequent hospitalizations. These characteristics were not explored in this study.

Several factors make interpretation of the finding of an association between a higher number of mental health contacts and a greater number of distal supports difficult. First, the distribution of hospitalizations and emergency contacts among this sample population was uneven; more than half the participants had no hospitalizations or emergency contacts and very few participants had three or more hospitalizations and/or emergency contacts (n = 9 and 11, respectively). Second, due to practical limitations on data collection, distinctions in the nature of the mental health contacts (i.e. partial vs. outpatient; resource coordination vs. continuous treatment team) could not be measured. Third, these results may be confounded by the fact that participants who more frequently make use of emergency and outpatient services may be finding sources of distal support with the providers of these services (i.e. casual interactions with staff).

E. PUBLIC HEALTH SIGNIFICANCE

In the United States, mental disorders collectively account for more than 15% of the overall burden of disease from all causes, slightly more than the burden associated with all forms of cancer (Murray & Lopez, 1996). Each year one in 10,000 persons will be diagnosed with schizophrenia and approximately 1.5% of the population will have an episode of schizophrenia in their lifetime; nearly 10% of those individuals will commit suicide. The cost of schizophrenia consumes approximately $65 billion per year in the United States, roughly 30% of which is in direct treatment costs. The remainder cost is absorbed by lost work productivity by patients and their caregivers, social services, and criminal justice costs (The Schizophrenia Homepage).

Research examining individuals diagnosed with schizophrenia have found that social contacts beyond the family and the mental health community are important to ratings of quality of life in this population (Borge, 1999). This study demonstrated that higher life satisfaction ratings and a greater sense of belonging are associated with the presence of distal supports and may have implications for future psychosocial intervention strategies in terms of expanding upon skills developed through psychosocial rehabilitation. Distal supports are by no means intended to be viewed as an end goal for individual's diagnosed with schizophrenia, but as a foundation upon which to build more meaningful social relationships.

This study demonstrated that participants who were extraverted and open to experience were more likely to engage in the community around them as measured by the number of distal supports. They were found to have a greater number of distal supports and to report higher

quality of life satisfaction and a greater sense of belonging. Although this study failed to find an association between distal supports and a reduced reliance on mental health services, it did identify personality factors that are associated with both.

F. STRENGTHS OF THE STUDY

Interest in casual sources of support has been growing. This study was designed to examine this source of support using a quantitative instrument specifically developed for this purpose.

- A measurement for collecting data on distal supports was developed and tested in this study.
- This study was designed specifically for the purpose of identifying the presence and sources of distal support.
- This study included 58 men and women, a larger number than in previous studies examining distal support.
- This study collected data on personality, quality of life, sense of belonging and demographic characteristics to explore factors associated with fostering distal supports.
- The sample size was adequately powered to detect moderate correlations.
- All data was collected by the same interviewer, thereby ensuring consistency.

G. LIMITATIONS OF THE STUDY

As with all studies, there are limitations that restrict conclusions. Potential limitations include:

- The validity of the Distal Support Measure is difficult to measure due to the lack of comparable instruments.
- Ratings on the Global Assessment of Functioning and Schizophrenia Rating Scale were based on observation and information obtained during a brief, non-clinical interview and therefore may not take into consideration symptoms and functioning that could not be elicited during the interview.
- Study limitations prohibited collecting data on the specific nature (e.g. individual or group psychotherapy, art therapy, crisis appointment, phone contact) of each outpatient contact or in which level of care the participant was enrolled (i.e. Partial Hospitalization, Outpatient, or Psychosocial Rehabilitation).
- Only 30 participants were enrolled in case management services. Furthermore, limitations on data collection prohibited collecting data on the level of case management received by the participant (i.e. Intensive Case Management, Resource Coordination, or Community Treatment Team).
- Although the inclusion criteria specified that the participant would have been in exclusive treatment at UPMC-WPIC, it is possible that a participant may have received treatment at another facility and would not be included in the data.

- This study employed a cross-sectional study design. Cross-sectional data does not allow causality to be established.
- The sample size was not large enough to adjust for confounding.

H. SUMMARY

Overall this study established that the personality factors of extraversion and openness play a role in the process of developing community distal supports, while the personality factor of neuroticism was found to have no effect on this process. Functional status and symptom severity were not found to be associated with a greater number of distal supports while higher quality of life satisfaction ratings and sense of belonging scores were significantly associated. Contrary to the stated hypothesis, a greater number of distal supports were associated with a higher number of mental health contacts. This may be due, in part, to the confounding effects of the personality factors of extraversion and openness; both associated with a higher number of distal supports and with a greater willingness to seek support and to accept treatment during times of need. It may also be due to the

Understanding the influence that personality factors have on successful community integration and tenure in individuals diagnosed with schizophrenia can be useful to tailoring therapeutic interventions based on individual needs. For instance, individuals who do foster distal supports in the community may be the most likely to benefit from psychosocial rehabilitation. Likewise, a demonstrated ability to form distal relationships may serve as a useful guide to assess readiness for less restrictive care or as a measure of progress in applying and further developing the social skills learned in rehabilitation in a natural setting.

Distal supports are not intended to be viewed as a satisfactory end goal for the individual diagnosed with schizophrenia. Although relationships of this nature may be helpful in promoting a sense of belonging and contributing to a higher overall life satisfaction, they do not satisfy the most basic human need for more deeply emotional relationships. Distal relationships can, however, be used as a foundation upon which to build meaningful relationships and to practice "being social" with the skills learned in psychosocial rehabilitation.

APPENDIX A

DISTAL SUPPORT MEASURE

Distal Support Measure

Participant Identification #_____ Date ____/____/____

Participant Initials _____

Community Support Systems Assessment:

Social Network:

a) Household composition: _____
_____

b) Extended family: _____
_____
_____

c) Nonkin (neighbors, friends, classmates, clubs, lodges, hangouts, etc)_____
_____
_____
_____
_____

Use of resources other than WPIC_____
_____
_____

Core support system (person counted on, turned to, or confided in):
_____
_____
_____
_____

The following questions will be asking about your experience talking with others you meet in the community, such as shop owners, wait staff, and employees who work in places you go. These places could be your pharmacy, a coffee shop, the library, community group or any place you go on a regular basis. I want you to focus only on your interactions and experiences with people you meet in the community, not people you meet at the clinic, the clubhouse, or with family members. Each question is asking about your experiences over the past 3 month's.

1. Where do you shop to make the majority of your grocery purchases?

0 = I do not do the grocery shopping.
1 = Where : _____**( ).**

a). How frequently do you shop in this store?
1 = Daily
2 = More than once per week
3 = Once per week
4 = More than once per month
5 = Monthly

b). How long have you been shopping regularly in this store?
1 = Less than one year
2 = One to five years
3 = Five or more years

c). Do you look forward to the time you spend shopping there?
1 = Yes
0 = No

d). Do the people there recognize/acknowledge you when you come in?
1 = Yes
0 = No

e). Do you feel welcomed there?
1 = Yes
0 = No

f). Do you know the names of people there?
1 = Yes
0 = No

g). Do they know your name?
1 = Yes
0 = No

h). Do they sometimes help you out in times of need (e.g. allowing you to pay for items later, etc.)
1 = Yes
0 = No
2 = Never asked
If yes, specify how:_____

i). Do you think they would help you out in times of need?
1 = Yes
0 = No

j). Do you consider any of them to be a friend or an acquaintance?
1 = Friend
0 = No
2 = Acquaintance

2. Where do you get your prescriptions filled?
0 = I do not get my prescriptions filled.
1 = Where : _____**( ).**

a). How frequently do you go to this pharmacy?
1 = Daily
2 = More than once per week
3 = Once per week
4 = More than once per month
5 = Monthly

b). How long have you been going there regularly?
1 = Less than one year
2 = One to five years
3 = Five or more years

c). Do you look forward to the time you spend there?
1 = Yes
0 = No

d). Do the people there recognize/acknowledge you when you come in?
1 = Yes
0 = No

e). Do you feel welcomed there?
1 = Yes
0 = No

f). Do you know the names of the people who work there?
1 = Yes
0 = No

g). Do they know your name?
1 = Yes
0 = No

h). Do they sometimes help you out in times of need (e.g. allowing you to pay for items later, etc.)
1 = Yes
0 = No
2 = Never asked
If yes, specify how:_____

i). Do you think they would help you in times of need?
1 = Yes
0 = No

j). Do you consider any of them to be a friend or an acquaintance?
1 = Friend
0 = No
2 = Acquaintance

3. Is there a restaurant or café you go to on a regular basis?
1 = Yes
0 = No
***If yes*,**
Specify:_____

a). How frequently do you go there?
1 = Daily
2 = More than once per week
3 = Once per week
4 = More than once per month
5 = Monthly
6 = Occasionally only

b). How long have you been going there regularly?
1 = Less than one year
2 = One to five years
3 = Five or more years

c). Do you look forward to your time there?
1 = Yes
0 = No

d). Do they recognize/acknowledge you when you come in?
1 = Yes
0 = No

e). Do you feel welcomed there?
1 = Yes
0 = No

f). Do you know the names of the people who work there?
1 = Yes
0 = No

g). Do they know your name?
1 = Yes
0 = No

h). Do they sometimes help you out in times of need (e.g. coffee on the house, allowing you to pay later, etc.)
1 = Yes
0 = No
2 = Never asked
If yes, specify:_____

i). Do you think they would help you out in times of need?
1 = Yes
0 = No

j). Do you consider any of them to be a friend or an acquaintance?
1 = Friend
0 = No
2 = Acquaintance

4. Is there a local store where you go on a regular basis?
1 = Yes
0 = No
*If yes,*specify:_____

a). How frequently do you go there?
1 = Daily
2 = More than once per week
3 = Once per week
4 = More than once per month
5 = Monthly
6 = Occasionally only

b). How long have you been going there regularly?
1 = Less than one year
2 = One to five years
3 = Five or more years

c). Do you look forward to your time there?
1 = Yes
0 = No

d). Do they recognize/acknowledge you when you come in?
1 = Yes
0 = No

e). Do you feel welcomed there?
1 = Yes
0 = No

f). Do you know the names of the people who work there?
1 = Yes
0 = No

g). Do they know your name?
1 = Yes
0 = No

h). Do they sometimes help you out in times of need (e.g. coffee on the house, allowing you to pay later, etc.)
1 = Yes
0 = No
2 = Never asked
If yes, specify:_____

i). Do you think they would help you out in times of need?
1 = Yes
0 = No

j). Do you consider any of them to be a friend or an acquaintance?
1 = Friend
0 = No
2 = Acquaintance

5. Do you belong to/attend a place of worship?
1 = Yes
0 = No

If yes,

a). How frequently do you attend?
1 = more than once per week
2 = weekly
3 = monthly
4 = holiday's only

b). How long have you been attending?
1 = Less than 6 months
2 = One to two years
3 = Two to five years
4 = Five or more years

c). Do you look forward to going there?
1 = Yes
0 = No

d). Do you feel welcomed there?
1 = Yes
0 = No

e). Do you know their names?
1 = Yes
0 = No

f). Do they know your name?
1 = Yes
0 = No

g). Do they sometimes help you out in times of need?
1 = Yes
0 = No
2 = Never asked
If yes, specify:_____

h). Do you think they would help you out in times of need?
1 = Yes
0 = No

i). Do you consider any of them to be a friend or an acquaintance?
1 = Yes
0 = No

6. Do you have other favorite places where you hang out on a regular basis? (e.g. club, AA/NA, etc.)
1 = Yes
0 = No
If yes,

Specify:_____

a). How frequently do you go there?
1 = Daily
2 = More than once per week
3 = Once per week
4 = More than once per month
5 = Monthly
6 = Occasionally only

b). How long have you been going there regularly?
1 = Less than one year
2 = One to five years
3 = Five or more years

c). Do you look forward to your time there?
1 = Yes
0 = No

d). Do they recognize/acknowledge you when you come in?
1 = Yes
0 = No

e). Do you feel welcomed there?
1 = Yes
0 = No

f). Do you know the names of the people who work there?
1 = Yes
0 = No

g). Do they know your name?
1 = Yes
0 = No

h). Do they sometimes help you out in times of need (e.g. coffee on the house, allowing you to pay later, etc.)
1 = Yes
0 = No
2 = Never asked
If yes, specify:_____

i). Do you think they would help you out in times of need?
1 = Yes
0 = No

j). Do you consider any of them to be a friend or an acquaintance?
1 = Friend
0 = No
2 = Acquaintance

7. Are there other places or circumstances where you are comfortable and have come to know people you've met independent of the clinic or through family and friends?
1 = Yes
0 = No
If yes,
Where?
1._____
2._____

Place 1: _____

a). How frequently do you go to there?
1 = Daily
2 = More than once per week
3 = Once per week
4 = More than once per month
5 = Monthly

b). How long have you been going there regularly?
1 = Less than one year
2 = One to five years
3 = Five or more years

c). Do you look forward to time spent there?
1 = Yes
0 = No

d). Do the people there recognize/acknowledge you when you come in?
1 = Yes
0 = No

e). Do you feel welcomed there?
1 = Yes
0 = No

f). Do you know their names?
1 = Yes
0 = No

g). Do they know your name?
1 = Yes
0 = No

h). Do they sometimes help you out in times of need (e.g. lending you money, buying you something)
1 = Yes
0 = No
2 = Haven't asked/needed
If yes, specify: _____

i). Do you think they would help you out in times of need?
1 = Yes
0 = No

j). Do you consider any of them to be a friend or an acquaintance?
1 = Friend
0 = No
2 = Acquaintance

Place 2: _____

a). How frequently do you go to there?
1 = Daily
2 = More than once per week
3 = Once per week
4 = More than once per month
5 = Monthly
6 = Occasionally only

b). How long have you been going there regularly?
1 = Less than one year
2 = One to five years
3 = Five or more years

c). Do you look forward to time spent there?
1 = Yes
0 = No

d). Do they recognize/acknowledge you when you come in?
1 = Yes
0 = No

e). Do you feel welcomed there?
1 = Yes
0 = No

f) Do you know other people who go there?
1 = Yes
0 = No

g). Do you know their names?
1 = Yes
0 = No

h). Do they know your name?
1 = Yes
0 = No

i). Do they sometimes help you out in times of need (e.g. lending you money, buying something for you)
1 = Yes
0 = No
2 = Never asked/needed
If yes, specify_____

j). Do you think they would help you in times of need?
1 = Yes
0 = No

k). Do you consider any of them to be a friend or an acquaintance?
1 = Friend
0 = No
2 = Acquaintance

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